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ABSTRACT

The plan presents information relating to persons with developmental disabilities and other substantial handicaps in Alaska. A joint effort by state planning and service providing agencies, the plan was developed with input from consumers as well as providers. An introduction to the document is followed by an overview of the state and the implications for planning. An overview of services addresses six major topics: (1) health services (prevention, early identification); (2) support services (maintenance, material support); (3) residential options (natural environments); (4) educational services (infant learning, post-secondary and adult education); (5) vocational services (prevocational training, job placement); and (6) enabling services (case management, guardianship). The remainder of the plan presents descriptions, target population, communities, levels and service flow patterns, services descriptions and utilization, and obstacles and opportunities for each of the seven regions of the state. (CL)

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Alaska State Plan

OF SERVICES FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES AND OTHER SUBSTANTIAL HANDICAPS

1984-1986

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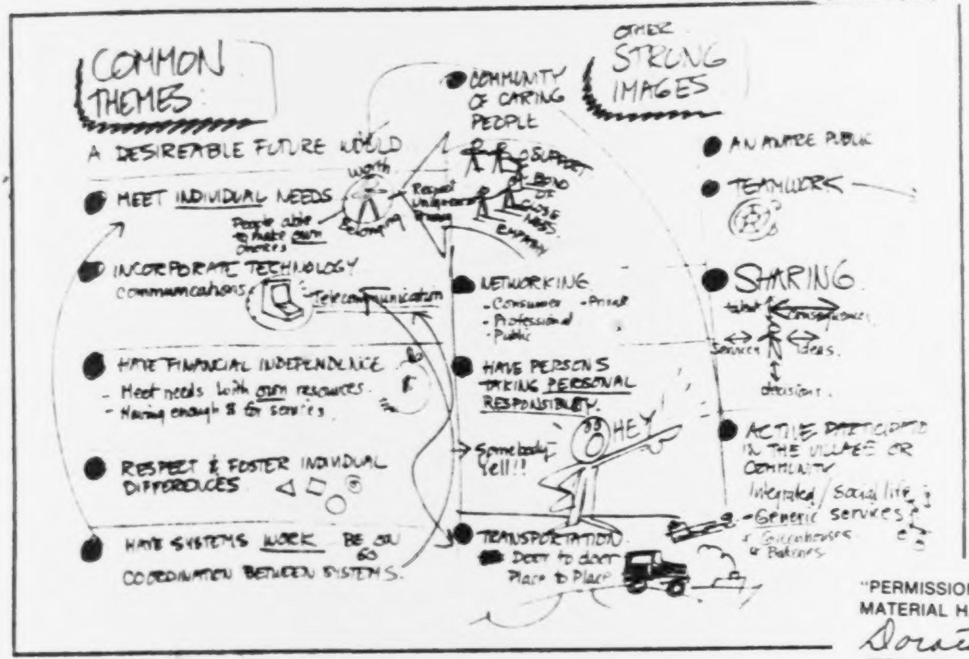
COMMON THEMES
A DESIREABLE FUTURE WOULD
MEET INDIVIDUAL NEEDS
worth
People able to make own choices
Belonging
Respect
INCORPORATE TECHNOLOGY
communications
Telecommunication
HAVE FINANCIAL INDEPENDENCE
- Meet needs with own resources.
- Having enough $ for services
RESPECT & FOSTER INDIVIDUAL DIFFERENCES
HAVE SYSTEMS WORK
COORDINATION BETWEEN SYSTEMS.
COMMUNITY OF CARING PEOPLE
SUPPORT
BOND OF CLOSENESS
EMPATHY
NETWORKING
- Consumer - Private
- Professional
- Public
HAVE PERSONS TAKING PERSONAL RESPONSIBILITY.
Somebody Yell!!
HEY
TRANSPORTATION
Door to door
Place to Place
OTHER STRONG IMAGES
AN AWARE PUBLIC
TEAMWORK
SHARING
talent
consequences
Services
Ideas.
decisions.
ACTIVE PARTICIPATION IN THE VILLAGE OR COMMUNITY
Integrated / Social life
- Generic services
Greenhouses
Bakeries

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CHAPTER 1

INTRODUCTION AND SUMMARY

CHAPTER 1

INTRODUCTION AND SUMMARY

Statement of Purpose

This plan presents information relating to persons with developmental disabilities and other substantial handicaps in Alaska. The plan was developed by the Alaska Governor's Council for the Handicapped and Gifted with the following purposes in mind:

advise citizens of Alaska about the Developmental Disabilities Basic State Grant Program, enable them to participate in the planning process and be knowledgeable about the manner in which services to people with developmental disabilities and other substantial handicaps operate in Alaska;

provide a framework within which citizens of the state, organizations, and agencies can work together to institute changes, develop services, and improve life-long opportunities for people with disabilities and their families in all regions of the state;

provide reliable, useful information to the federal government for use in developing national policy regarding the Basic State Grant Program and the needs of people with developmental disabilities and other substantial handicaps;

meet the requirement set by Congress in Public Law 95-602 as amended by Public Law 97-35, that states wishing to participate in Part C of the Developmental Disabilities Assistance and Bill of Rights Act comply with provisions of the law. The plan therefore represents a contract between the State of Alaska and the Federal government for receipt of funds under the Act.

Description of Process

The plan is a joint endeavor of the Council, the Department of Health and Social Services' Division of Mental Health and Developmental Disabilities, which is the state agency responsible for administering federal developmental disabilities funds, and other planning and service providing agencies. Development of the plan was supervised by the Council's Planning Committee. The Council recognizes the significant assistance provided by the Northern Alaska Health Resources Association, one of the three health systems agencies in Alaska.

The triennial plan for Fiscal Years 1984 through 1986, follows major plans completed by the Council in 1978 and 1981 and annually up-dated. As part of the on-going planning activities of the Council, the service priority areas of child development services and alternative community living arrangement services were again selected as priorities for the three year plan period.

Development of the plan document involved consumers and providers through surveys, interviews, correspondence, meetings, and review of planning documents.

Comments and suggestions are solicited on a continuing basis for use in annual revisions and other reports on services and priorities prepared by the Council.

Organization of the Plan

Regionalization

Previous Developmental Disabilities State Plans have looked at the state as a whole while dividing the state into seven planning regions for purposes of data analysis and display within the major service categories. A major change in the FY 1984-1986 plan is the total regionalization of the plan format. Each of the seven planning regions, North, Northwest, Central, West, Southwest, Southcentral, and Southeast, is described in depth in terms of population, cultures, economy, target population, cultures, communities, services, service flow patterns, available services, service utilization and needs, and obstacles and opportunities.

This major re-formatting of the plan was necessary to recognize significant developments which have taken place since the 1978 plan was completed. Regional and sub-regional infrastructures for human services now exist because of ANCSA, the Alaska Native Land Claims Settlement Act. Regionalization also draws attention to the diversity of the state and its people, provides for more graphic displays of the distribution of services, and provides sufficient detail for real service planning in the future.

Regionalization is consistent with the policies of the new state administration and with the Council's support for decentralization of services and local planning.

Levels of Service

Another major improvement in the plan is incorporation of the health systems agencies' "levels of care" concept related to levels of communities. For a long time the health planning agencies have utilized a levels of care system as a framework for making recommendations about service systems and resource needs. The Council has adopted this framework and developed levels of care for the array of services needed to meet the life-long needs of people with disabilities.

Levels of community are determined according to factors such as accessibility, proximity, transportation, communication, economic development, and population. Villages are Level I; Sub-regional centers, Level II; Regional Centers, Level III; and Urban Centers, Level IV. Appropriate services are identified for each community level according to several other factors.

These level of care guidelines provide a basis for planning, budgeting, and service delivery design. They will help articulate service systems for the future.

Levels of care add another dimension to the state's Services Planning Framework which looks at services along a continuum from least restrictive to most restrictive, from natural to protective, and according to the time of day services are needed--daytime, evening, or overnight. It will be seen that there is consistency between the smallest service unit, Level I communities, and the least restrictive services, those which can be provided in natural family settings by generic agencies.

This framework may provide another stimulus for development of services from the ground up, starting with the simplest and smallest and leading to the largest and most sophisticated rather than the other way around.

Target Population

People with developmental disabilities have needs which are often similar to people who are disabled due to accident, injury, and aging. The Council has continued to focus on the similarities because of the obvious benefits and efficiencies which can result from planning for a larger sub-population rather than isolating sub-groups in the planning process. Alaska's small population and the dispersal of that population in many communities require sharing of resources across these groups especially at the village and sub-regional levels.

The Council has continued to include the expanded population of people with developmental disabilities and other substantial handicaps, 12,625 Alaskans, in the target population for planning and advocacy.

Sections of the Plan

The plan begins with an overview of Alaska, the general population and the target population. Also discussed in Chapter Two are other demographic factors such as economy, geography, poverty, cultural groups, and major health status indicators. Chapter Three describes the services framework in Alaska and the context within which services to people with disabilities operate. The role of the Council is discussed along with laws and regulations, service principles, the services planning construct and the levels of care recommended by level of community.

The overview of services in Chapter Four describes the life-long services people with disabilities may need and agencies and programs which provide them.

Chapters Five through Eleven are the seven regional chapters which describe each region, the services specific to that region and the communities which comprise it.

The Appendices include information and assurances required by the federal government as well as back-up data and bibliography of references. A copy of the State's umbrella statute for services to people with disabilities, A.S. 47.80, is included along with information on Council membership and staff of the Council and the state administering agency.

Major Concerns During the Three-Year Plan Period

Major concerns during the three year plan period are reflected in the regional and summary chapters of the plan, particularly in the Obstacles and Opportunities sections.

These issues are: statutory reform in A.S. 47.80 and A.S. 14.30; promulgation of program standards and regulations; service development in the priority service areas; elimination of inappropriate institutionalization; increased funding for home-based and community-based services; capacity-building and improvements in quality in the generic system.

The Council's planning process involves consumers, providers, local and state agency officials, and the public at large through participation in committee meetings, opportunities to present concerns at every Council member, public notice of meetings, A-95 review process, and on-going data-collection, surveys, and consultations with agencies and groups plus sponsorship of local planning conferences called "Search" conferences.

Survey results, client data, correspondence, communications, projects data and reports, allied agency plans and surveys, and special reports are analyzed and utilized to identify issues, develop strategies, and select service priorities.

Priority Service Areas

The federal Developmental Disabilities Act requires each state to assess the service needs of all developmentally disabled citizens, with special emphasis on four service areas identified in the legislation as requiring special consideration. These four areas are:

A. Case Management: Services which will assist persons with in gaining access to needed social, medical, educational and other services; includes follow-along services which ensure a continuing relationship, lifelong if necessary, between a provider and a person with developmental disabilities and the person's immediate relatives or guardians; includes coordination services which provide support, access to and coordination of other services, information on programs and services and monitoring of progress. (Section 102(8)(C)(i)(ii))

B. Child Development Services: Services which will assist in the prevention, identification, and alleviation of developmental disabilities in children, and includes early intervention, counseling and training of parents, early identification and diagnosis and evaluation. (Section 102(8)(D)(i)(ii)(iii)(iv))

C. Alternative Community Living Arrangement Services: Services which will assist persons in maintaining suitable residential arrangements in the community, including in-house services (such as personal aides and attendants and other domestic assistance and supportive services) family support services, foster care services, group living services, respite care, and staff training, placement, and maintenance services. (Section 102(8)(E))

D. Non-Vocational Social-Developmental Services: Services which will assist persons in performing daily living and work activities. (Section 102(8)(F))

Elements of these priority service areas and services in Alaska are fully described in Chapter Four, Overview of Services, and in each of the Regional Chapters, Chapters Five through Eleven. The state's framework for looking at and developing these service elements statewide is addressed in Chapter Three.

Alaska's Priority Service Areas

Alaska has selected the following service priority areas for special emphasis during the next three years:

Child Development Services

- Infant Learning Programs
- Vision and Hearing Screening
- Educational services to children with low-incidence handicaps
- Occupational, physical, and speech therapy
- Family Counseling and Training
- Prevention and Public Awareness of Disabilities

Alternative Community Living Arrangements

- Support Services
  - Maintenance - day care, respite, homemakers, aides
  - Developmental - personal skills and independent living skills training
  - Material Support - financial assistance, adaptive equipment
- Residential Options
  - Natural and Augmented Environments - family care, foster care, adoptions, semi-independent living programs
  - Devised Environments - group homes, community residences for 5 or less

These priorities were selected by the Council based on activities and input over the last three years. Descriptive information is contained in Chapters Two through Twelve.

Alaska's Goals for Services for People with Disabilities

Provide local opportunities for every child with a disability to begin to receive educational and developmental services in infancy and to look forward to life-long educational services and opportunities through adult learning, community schools, and post-secondary programs.

Change funding patterns to those which empower local entities and consumers to purchase services and to those which provide incentives for community-based services.

Plan and advocate for funding and development of family support and community living services so that all people with disabilities may eventually be served in their home communities or in their home region.

Increase the knowledge and skills of service providers, families, and the public to improve the availability, accessibility, flexibility, and range of services, particularly of generic services.

Encourage formation and utilization of regional and local planning and support groups for the design and delivery of services.

Foster the use of multiple approaches to development of home-based community services to reduce and eliminate inappropriate institutionalization.

Improve administrative systems for services through revision and strengthening of A.S. 47.80 and A.S. 14.30, improvements in program standards, program regulations, methods for allocating funds, awarding contracts or grants, evaluating services, and monitoring programs.

Advocate for full special education funding, special education funding formulas, and funding accountability for all special education and related services in the state.

Promote efforts to coordinate the development and delivery of the full range of vocational education, career education, vocational training, job placement, sheltered workshop, and day-time services for people with disabilities beginning in junior high school and continuing through adulthood.

For information on FY84 objectives for the Council the Council's Work Plan is included in the Appendix.

A Few Words About Planning

Like most other planning groups, the Governor's Council for the Handicapped and Gifted has struggled with the concepts of planning. Usually development of a planning document such as the Developmental Disabilities State Plan is anticipated with dread on the part of staff and planning committees and its completion is met with sighs of relief. It's as if the plan was "it", now to be put aside until the next external deadline for another "plan" forces us to repeat the process.

The Council has jumped through the usual planning hoops. Council members and staff, along with agency people, have caused and sponsored a series of different kinds of planning activities over the past five years. While sponsorship of a task force to develop a plan for "Outreach Special Education Services to Students with Low-Incidence Handicaps" and completion of a three-year effort to facilitate home support services planning in the central region may seem unrelated, they represent alternative planning processes. Along with numerous other projects and activities, they reflect the Council's awareness that there are many forms of planning and influencing. They affirm the Council's commitment to realization of the goals and service principles included by the Alaska Legislature in A.S. 47.80.

Those visions of the future and the ways to get there include some type of jointly planned and implemented comprehensive system of services with services designed to "maximize individual potential, minimize institutionalization, and to be provided in the least restrictive setting, enabling a person to live as normally as possible within the limitations of the handicap." (A.S. 47.80.110)

The services are to be dispersed geographically within the state. They may include special adaptations of services available to the general public and specialized services.

The state plan attempts to set a framework for accomplishing these goals and moving us toward that desirable future of individualized, localized services which respect individual differences and support people living in their own homes and communities. This plan does not present a litany of detailed recommendations. Experience has taught us that setting up "shoulds" for other people is not likely to be an acceptable or successful strategy unless there is direct ability to control outcomes. More likely to succeed is presentation of a menu from which items can be selected according to preference and need. This plan seeks to provide that so any service provider, local government, consumer group or private individual can seek information, learn about alternatives, and obtain assistance. It is intended as a basis for many different activities in each of the seven regions and in the various divisions and departments of state government.

CHAPTER 2

AN OVERVIEW OF ALASKA

General Population and Population Growth

Alaska's population is quite small, 401,851 in 1980, but is expected to grow at a 3.59% average annual increase to a population of 528,384 by 1988. This growth rate is approximately double the national average. Historically, Alaska experienced a tremendous in-migration from the "Lower 48". There are some areas of the state which are predicted to experience very rapid population growth. These include the Matanuska-Susitna Borough (17.62% average annual growth rate - 1970 to 1988), the North Slope (9.61%), and the Kenai Peninsula (5.44%).

The rural areas of the state are expected to experience moderate or only slight population increases. The population growth of Alaska has been and is predicted to be significantly influenced by private sector development activities. Currently, there is speculation that a gas line will be constructed from the North Slope of Alaska to tie with a Canadian gas line. There are increased oil and mineral exploration activities on the outer continental shelf areas as well as in some areas of the Central Region and Northwestern Regions. Until private sector decisions are made in regard to these resource development projects, one cannot firmly predict the population patterns which may accompany these developments. See Table 2-1 for 1980 population information and the appendices for projections to 1988.

TABLE 2-1

1980
ALASKA POPULATION DATA

	Age Groups					
Region	0-2	3-5	6-20	21-64	65+	Total
Northern	275	214	1,265	2,297	148	4,199
Northwest	812	734	3,759	5,475	588	11,368
Central	4,308	3,782	17,604	40,112	1,726	67,532
Western	1,114	1,084	5,486	7,371	609	15,664
Southwest	317	285	1,783	3,131	194	5,710
South Central	14,525	12,607	64,146	146,572	5,734	243,584
Southeast	3,110	2,738	13,884	31,514	2,548	53,794
STATEWIDE	24,461	21,444	107,927	236,472	11,547	401,851

Source: U.S. Department of Commerce, Bureau of the Census. 1980 Census of Population, General Population Characteristics, Part 3 Alaska. PC 80-1-B3 Alaska, Washington, D.C. August 1982. Pp. 3-56, 3-57.

Generally age group distribution is as follows: 6% ages 0-2, 5.3% ages 3-5, 26.9% ages 6-20, 58.8% ages 21-64, and 2.9% ages 65 and older.

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Regional Areas

Alaska has no one set of officially recognized regional boundaries. This plan divides Alaska into seven service regions. These regions are comprised of 1980 census divisions and regional Native corporations shown in Table 2-2.

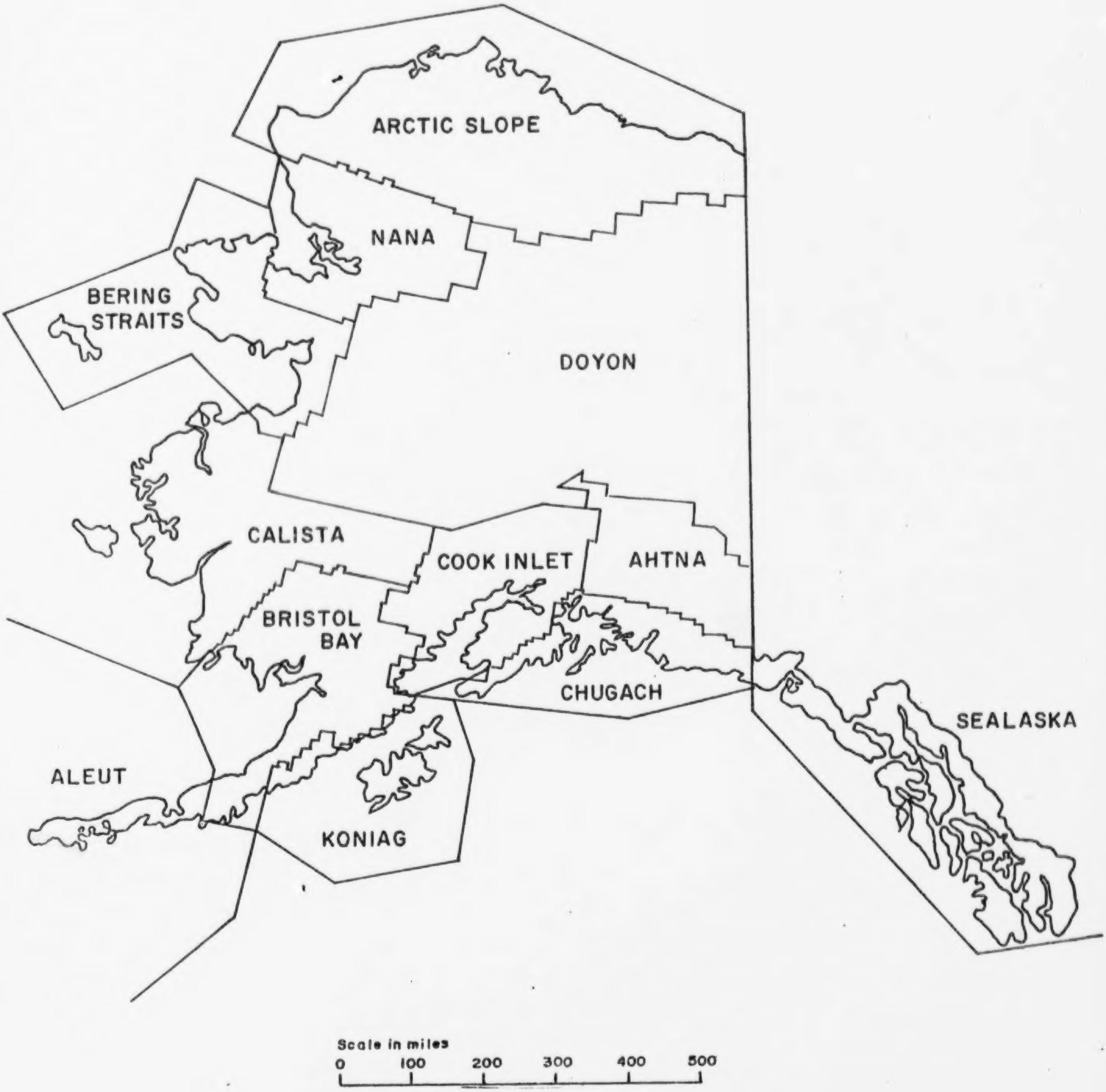
Ninety percent of Alaska's population is located in the southeast, southcentral, and central regions of the state. The largest city, Anchorage, located in southcentral Alaska, contains 43.4% of the total state population. The remaining 10% of the state's population is scattered in the small communities and villages of the "bush" areas of the state - the north, northwest, west, and southwest regions.

TABLE 2-2

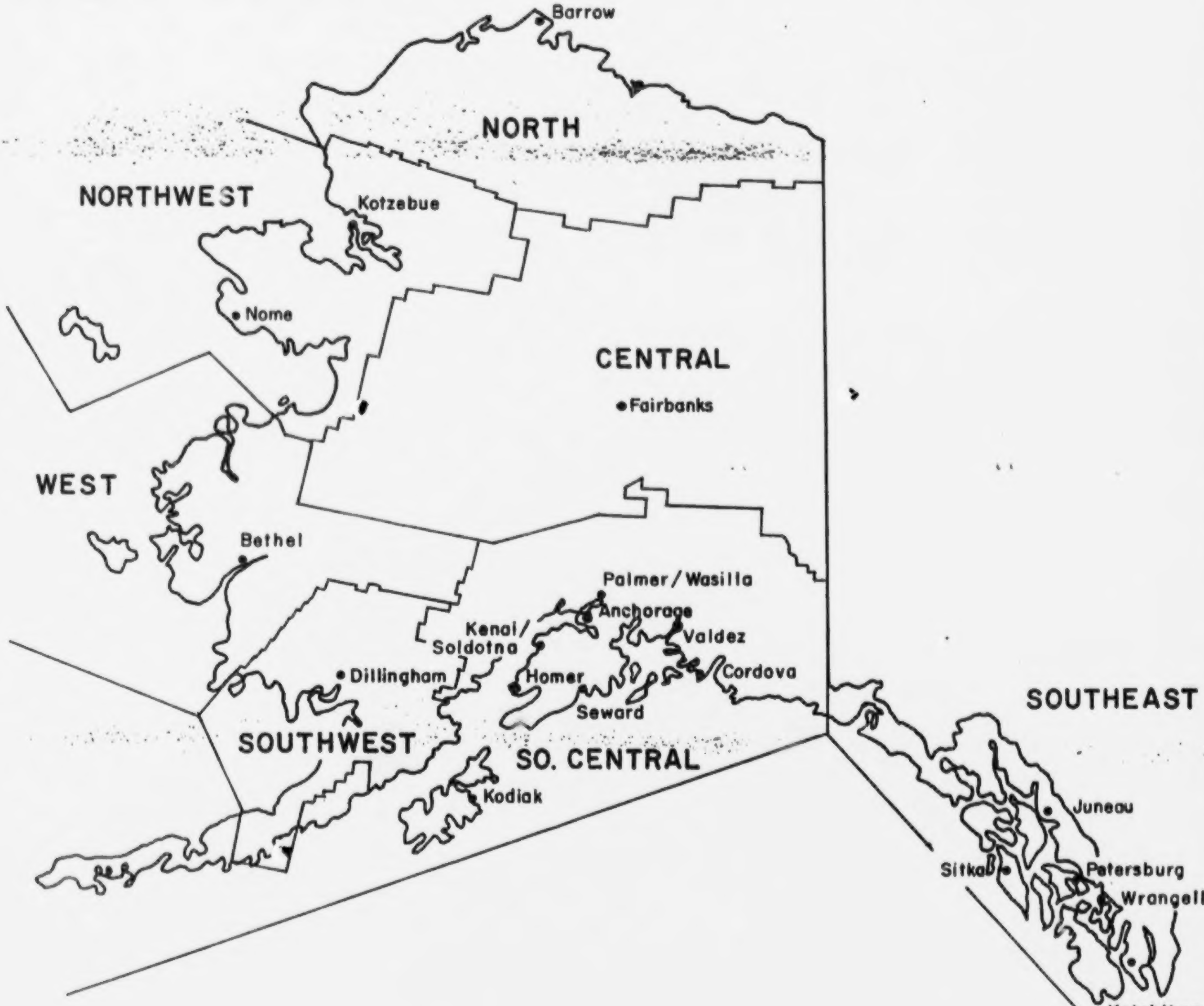
ALASKA REGIONAL COMPOSITION

REGION	NATIVE NON-PROFIT CORPORATIONS	CENSUS DIVISIONS
North	North Slope Borough Health Department	Borough
Northwest	Norton Sound Health Corporation, Mauneluk Association	Nome, Kobuk
Central	Tanana Chiefs Health Authority	Fairbanks, Southeast Fairbanks, Yukon-Koyukuk, Upper Yukon, Kuskokwim
Western	Yukon-Kuskokwim Health Corporation	Bethel, Wade Hampton
Southwest	Bristol Bay Area Health Corporation	Bristol Bay Borough, Bristol Bay
South Central	Copper River Native Association, North Pacific Rim Native Corporation, Kodiak Island Native Health Authority, Cook Inlet Native Health Authority, Aleut League	Cordova-McCarthy, Valdez-Chitina-Whittier, Kodiak, Seward, Kenai-Cook Inlet, Anchorage, Aleutian Islands, Matanuska-Susitna
Southeast	Southeast Alaska Regional Health Corporation	Skagway-Yakutat, Sitka, Angoon, Haines, Juneau, Wrangell-Petersburg, Prince of Wales, Ketchikan, Outer Ketchikan

ALASKA'S NATIVE REGIONS


ARCTIC SLOPE
NANA
BERING STRAITS
DOYON
CALISTA
COOK INLET
AHTNA
BRISTOL BAY
CHUGACH
SEALASKA
ALEUT
KONIAG
Scale in miles
0
100
200
300
400
500

ALASKA SERVICE REGIONS


Barrow
NORTH
NORTHWEST
Kotzebue
Nome
CENTRAL
Fairbanks
WEST
Bethel
Palmer / Wasilla
Anchorage
Kenai/
Soldotna
Valdez
Cordova
Dillingham
Homer
Seward
SOUTHEAST
SOUTHWEST
SO. CENTRAL
Kodiak
Juneau
Sitka
Petersburg
Wrangell
Ketchikan
Scale in miles
0
100
200
300
400
500

Ethnic and Age Composition

Statewide, Alaska Natives comprise approximately 16% of the population. Other minority groups comprise approximately 7% of the population. The remaining 77% of the population is Caucasian. Geographically, the "bush" areas of the state have a very high proportion of Alaska Native population, ranging up to 90% in certain areas of the north, northwest, west, and southwest regions. In the central, south central, and southeast regions of the state, the vast majority of the population is non-Native.

Alaska has a relatively young population. The median age of Alaskans was 26.1 years in 1980 compared with an median age nationwide of 30.0 years. There are relatively very few elderly people in the state, 2.9%, compared to approximately 11% nationwide. This age distribution difference of Alaska's population is probably due to the tendency for people to relocate to warmer climates upon retirement, the in-migration of people of child-bearing age and consequent presence of a significant number of infants and young children, and the in-migration of single individuals to work in pipeline and exploration-related occupations.

Income and Poverty

Alaska's per capita income was estimated at $12,790 in 1980, the highest of any state in the nation. However, if this figure is adjusted to the cost of living the figure changes significantly. In 1979 the U.S. Department of Labor calculated Alaska's adjusted per capita income at $7,501, compared to $8,706 nationwide.

1983
POVERTY INCOME GUIDELINES FOR ALASKA

Size of Family Unit	Poverty Guidelines
1	$ 6,080
2	8,180
3	10,280
4	12,380
5	14,480
6	16,580
7	18,680
8	20,780

For family units with more than 8 members, add $2,100 for each additional member.

Source: Federal Register, pages 7010-7011, February 17, 1983.

Alaska was estimated to have a population of 22,950 persons below the federally established poverty levels in 1975, or 6.3% of the Alaskan population compared to 11.3% in poverty nationwide. There is concern that these poverty levels are not appropriate for Alaska due to the high cost of living, and that the population in poverty is underestimated. In general, the population of the rural regions of the state has a lower income than does the population of the urban areas of the state. Table 2-3 indicates the 1970 census divisions which were considered poverty areas because over 20% of the population was living with incomes below national poverty thresholds.

Subsistence lifestyles and activities reduce the cash requirements of bush families. Some of these families will show up in statistical reports as being below the poverty level even though they may not be living an economically deprived existence. In 1970, according to Community Services Administration data, the non-native people below poverty level were mostly urban, and the Native people below poverty level lived mostly in the bush. Many of those probably had subsistence lifestyles.

TABLE 2-3

ALASKA POVERTY AREAS DESIGNATED
1970 CENSUS

Region/Census Division	Population	Population Under Poverty	Percent
North			
Barrow	2,599	689	26.51
Northwest			
Kobuk	4,267	1,609	37.70
Nome	5,544	1,966	35.46
Central			
Kuskokwim	1,983	1,206	60.81
Upper Yukon	1,517	399	26.30
Yukon-Koyukuk	4,235	1,065	25.14
West			
Bethel	7,475	4,738	63.38
Wade Hampton	3,858	2,564	66.45
Southwest			
Bristol Bay	3,558	1,279	35.94
South Central			
Matanuska-Susitna Borough	6,403	1,468	22.92
Southeast			
Angoon	463	434	93.73
Outer Ketchikan	1,690	401	23.72
Yakutat Portion of Skagway-Yakutat	1,264	357	28.24

Areas with more than 21.92% of population below poverty levels.

Source: Public Health Service, U.S. DHEW, Policy Notice 78-06, 1978.

People with Substantial Handicaps

The target population of this plan is people who are substantially handicapped. The definition of this population is as follows:

> A person with a substantial handicap is a person who has a severe, chronic disability which:
>
> - usually originated in childhood or before age 22;
> - is attributable to mental or physical impairments or a combination of mental and physical impairments;
> - is likely to continue indefinitely;
> - results in substantial functional limitations in three or more of the following areas of major life activities:
>   - self care,
>   - receptive and expressive language,
>   - learning,
>   - mobility,
>   - self-direction,
>   - capacity for independent living,
>   - economic self-sufficiency;
> - reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.

This target population is a larger and more diverse population than the "developmentally disabled" under either Public Law 95-602 or Alaska Statute 47.80. The target population includes all of those people who are defined as "developmentally disabled" under these federal and state laws plus adults whose disabling conditions occurred after they had become adults. The common characteristics are severity of impairment, chronicity, resultant functional limitations, and need for extended services. The major difference is that most developmentally disabled people never enjoyed full functioning without a disability whereas those substantially handicapped non-developmentally disabled people may have grown up without limiting physical or mental conditions.

In Alaska, because of small total population and the great similarities of needed service system responses, there seems to be little practical purpose in separating the populations for planning or service purposes. The differences within the one larger group are dealt with in the context of selection of services or service emphasis. For example, persons with mental disabilities require different service system response than those with physical disabilities even though both, at some point, may need assistance with employment, housing, education, or medical care.

Statewide, it is estimated that there are approximately 12,645 people who are "substantially handicapped" or approximately 3.1% of the total population. Approximately 55% of this target population is comprised of persons who are classified "developmentally disabled" by either the state or federal definition. The remaining 45% of this target population is comprised of people who are substantially handicapped as a result of causes other than developmental disabilities.

The only difference between the federal definition of developmental disability and the definition of substantial handicap presented here is insertion of the word "usually" to allow for similarly disabled people whose disabilities occurred after age 22. The appendix includes federal and state definitions of developmental disability, exceptional child and substantial handicap.

TABLE 2-4

ALASKANS WITH SUBSTANTIAL HANDICAPS
BY AGE RANGE AND TYPE of HANDICAP - 1980

		Substantially Handicapped Population		Type of Handicap	
Age Range	Total Population	Number	% of Total Age Range Population	D.D. P.L. 95-602	Other A.S. 47.80.900(6)
0-2	24,461	732	3%	732 [a]	0
3-5	21,444	643	3%	643 [b]	0
6-20	107,927	2,018	1.87%	2,018 [c]	0
21-64	236,472	8,020	3.39%	3,524 [d]	4,496 [f]
65+	11,547	1,212	10.5%	57 [e]	1,155 [g]
TOTAL	401,851	12,625	2.26%	6,974	5,651

P.L. 95-602 Functional Definition:

(a) 3.0% of population 0-3
(b) 3.0% of population 3-5
(c) 1.87% of population 6-20
(d) 1.49% of population 21-64
(e) 0.5% of population 65+
(f) 1.9% of population 21-64
(g) 10.0% of population 65+

Sources: Governor's Council for the Handicapped & Gifted, 1981 Developmental Disabilities State Plan; Boggs & Henney 1976 Survey of Income and Education; Urban Institute, Older Alaskans Commission.

Persons with Developmental Disabilities

The substantially handicapped population in Alaska with developmental disabilities totals 6,974 or 55%. There are two groups of developmentally disabled people to be considered in Alaska:

- persons who are developmentally disabled under P.L. 95-602; (Table 2-7)
- persons who are developmentally disabled under A.S. 47.80. (Table 2-8)

Public Law 95-602 includes people with mental or physical impairments as long as there are substantial functional limitations in three or more of the major life activity areas described above.

The predecessor of P.L. 95-602 was P.L. 94-103. That federal law included people with mental retardation, cerebral palsy, epilepsy, or autism or other impairment of intellectual functioning or adaptive behavior similar to mental retardation. The focus was on mental impairment, specifically mental retardation, and the definition was categorical and exclusive. People with severe physical, orthopedic, or health impairments, or emotional problems were not included. At the time of introduction and passage of a state developmental disabilities law, P.L. 94-103 was in effect. It was therefore included as part of Alaska Statute 47.80 which was enacted in 1978, and has been the state's definition for state-funded services since then.

All of the people included under A.S. 47.80 or P.L. 94-103 were also included under P.L. 95-602 because of the requirement for the handicap to be a substantial impediment to normal functioning in society. However, some of the people included under the new federal law, P.L. 95-602, are left out of the state law and therefore are not eligible to receive state-funded developmental disabilities services. This group totals 1,681 individuals, or 24% of the developmentally disabled population.

These people are generally people who are not mentally retarded or mentally impaired but who have significant physical or emotional handicaps which occurred or began during childhood. While these people are included under special education laws and receive public special education services, they are not eligible for community developmental disabilities services such as respite care, vocational training, or residential services.

TABLE 2-5

ALASKANS WITH SUBSTANTIAL HANDICAPS

<table>
<tr><td colspan="5">Total Population with Substantial Handicaps
12,625
A.S. 47.80.900(6)(9)</td></tr>
<tr><td>Age 0-2</td><td>Age 3-5</td><td>Age 6-20</td><td>Age 21-64</td><td>Age 65+</td></tr>
<tr><td>(6%)
732</td><td>(5%)
643</td><td>(16%)
2,018</td><td>(64%)
8,020</td><td>(9%)
1,212</td></tr>
</table>

<table>
<tr><td colspan="2">People with Developmental Disabilities As Defined by P.L. 95-602
(55%)
6,974</td><td rowspan="2">People with Other Substantial Handicaps
(45%)
(not eligible for state DD services)
5,651</td></tr>
<tr><td>Developmentally Disabled People Eligible for State DD Services
A.S. 47.80.900(7)
5,347</td><td>DD People not eligible for State DD Services
1,631</td></tr>
</table>

TABLE 2-6

REGIONAL POPULATIONS OF ALASKANS WITH SUBSTANTIAL HANDICAPS

Region	Age 0-2		Age 3-5		Age 6-20		Age 21-64		Age 65+		TOTAL		GRAND TOTAL
	DD	Other	DD	Other	DD	Other	DD	Other	DD	Other	DD	Other	
North	8	0	6	0	24	0	34	47	1	15	73	62	135
Northwest	24	0	22	0	70	0	82	104	3	59	201	163	364
Central	129	0	113	0	329	0	598	762	7	173	1,176	935	2,111
West	33	0	33	0	103	0	110	140	3	61	282	201	483
Southwest	10	0	9	0	33	0	47	59	1	19	100	78	178
South Central	435	0	378	0	1,200	0	2,183	2,785	29	573	4,225	3,358	7,583
Southeast	93	0	82	0	259	0	470	599	13	255	917	854	1,771
STATEWIDE	732	0	643	0	2,018	0	3,524	4,496	57	1,155	6,974	5,651	12,625

DD = Handicap result of developmental disability, P.L. 95-602.
Other = Handicap cause other than developmental disabilities.

Sources:

U.S. Department of Commerce, Bureau of Census. 1980 Census of Population, General Population Characteristics, Part 3 Alaska. PC 80-1-B3 Alaska. Washington, D.C. August 1982. Pp. 3-56, 3-57.
Governor's Council for the Handicapped and Gifted. Fairbanks, Alaska. 1981-83 Alaska DD State Plan. August, 1980. Pp. 25-29.
Urban Institute Report of the Comprehensive Service Needs Study. DHEW-RSA. June 23, 1975. Pp. 57-58, 72.
Alaska Division of Vocational Rehabilitation. 1983 Budget Narrative. Juneau, Alaska. January 1982.
Older Alaskans Commission. Lawry Robertson, Consultant - Phone Interview, January 1983.

Persons with Other Substantial Handicaps

The subgroup of persons who are substantially handicapped because of causes other than developmental disabilities comprises approximately 45% of the total population of persons with substantial handicaps in Alaska. These people are adults who became disabled after the age of 22. Their disabilities substantially limit them in at least three of the seven major life activity areas.

Some of these people are ineligible for Division of Vocational Rehabilitation services because their handicap is so severe. Additionally, there is currently no comprehensive statewide services system to address the service needs of this group. The service needs of this group (approximately 4,500 people, age 21-64, see Table 2-6) are very similar to adults with developmental disabilities, especially in areas such as the need for support services, residential options, and vocational services. That is why A.S. 47.80 requires comprehensive planning and services for this larger, combined group of people. Most are ineligible for state d.d. services because of the definition in state law, A.S. 47.80.900(7).

Ten percent of the elderly population (or approximately 1,150 people) is thought to be substantially handicapped. For purposes of need for home support services, particularly in low-density areas such as villages and subregional centers, it makes sense to consider the needs of older people who may be substantially handicapped along with the service needs of substantially handicapped younger people.

Conditions Which May Cause Substantial Handicaps

The developmentally disabled and substantially handicapped population does not include people who are mildly handicapped (such as people who are borderline mentally retarded) or whose handicaps are of a short-term nature (such as persons who have broken a bone and are in a cast for a couple of months). The target population does include people who have substantial, chronic problems and who are likely to need long-term, individualized services. Examples of conditions which could cause substantial handicaps are:

Condition		Definition
Mental Retardation	-	"...(a) significantly sub-average general intellectual functioning existing concurrently with deficits in adaptive behavior and manifest in the developmental period". (American Association on Mental Deficiency)
Epilepsy	-	a chronic symptom of cerebral dysfunction, characterized by recurrent attacks involving changes in the state of consciousness, sudden in onset and brief in duration; many attacks are accompanied by a seizure in which the person falls involuntarily. (DD-The Orientation Notebook)

Cerebral Palsy - a disorder dating from birth or early infancy which is non-progressive and characterized by disturbances in the body's motor functions (paralysis, weakness, incoordination) and often other manifestations of organic brain damage such as sensory disorders, seizures, mental retardation, learning difficulties, and behavioral disorders.
(DD-The Orientation Notebook)

Autism - a syndrome described as consisting of withdrawal, very inadequate social relationships, monotonously repetitive motor behavior, exceptional object relationships and language disturbances.
(DD-The Orientation Notebook)

Serious Emotional Disturbance, - a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree:

A. An inability to learn which cannot be explained by intellectual, sensory, or health factors;

B. An inability to build or maintain satisfactorily interpersonal relationships with peers and teachers;

C. Inappropriate types of behavior or feelings under normal circumstances;

D. A general pervasive mood of unhappiness or depression; or

E. A tendency to develop physical symptoms or fears associated with personal or school problems; conditions such as psychosis and schizophrenia.

(P.L. 94-142, 34 D.F.R. 300.5(b)8, The DD-Orientation Notebook)

Health Impairment - limited strength, vitality, or alertness due to chronic or acute health problems such as a heart condition, tuberculosis, rheumatic fever, nephritis, asthma, sickle cell anemia, hemophilia, lead poisoning, leukemia, or diabetes.
(P.L. 94-142 C.F.R. 300.5(b)7.)

Severe Physical Impairment - a disorder such as spina bifida, muscular dystrophy, and multiple sclerosis.
(DD-The Orientation Notebook)

Specific Learning Disability - a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which may manifest itself in an imperfect ability to listen, think, speak, read, write, spell, or to do mathematical calculations. The

term includes such conditions as perceptual handicaps, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia.
(P.L. 94.142, 34 C.F.R. 300.5(b)9)

Visual Impairment - an impairment involving loss of sight which, even with correction, adversely affects ability to function normally. The term includes both partially seeing and blind people.
(Adapted from P.L. 94-142, 34 C.F.R.)

Hearing Impairment - "Deaf", a hearing impairment which is so severe that a person is impaired in processing linguistic information through hearing, with or without amplification and "hard of hearing", a hearing impairment, whether permanent or fluctuating impairment.
(Alaska Special Education Handbook-1978)

Orthopedic Impairment - an impairment caused by congenital anomaly (e.g., clubfoot, absence of some member, etc.), impairment caused by disease (e.g., poliomyeletitis, bone tuberculosis, etc.), and impairment from other causes (e.g., cerebral palsy, amputations, and fractures or burns which cause contractures).
(P.L. 94-142, 34 C.F.R. 300.5(b)6)

Neurologically Handicapped - descriptive of persons who are disabled by a condition of the central nervous system, such as epilepsy, cerebral palsy, postencephalitis, or postmeningitis.
(Alaska Special Education Handbook-1978)

Communicative Disorder - impairment in articulation, language, voice, or fluency. A communicative disorder may range from a mild to severe developmental, organic, or psychogenic deficit.
(Alaska Special Education Handbook-1978)

Tables 2-6 and 2-7 display the Council's estimate of the number of substantially handicapped persons by region in the state and also by cause of handicap.

For detailed information about these conditions and causes of developmental disabilities and other handicapping conditions, refer to the 1978 Alaska Developmental Disabilities State Plan.

TABLE 2-7

ALASKA
PREVALENCE OF PERSONS WITH DEVELOPMENTAL DISABILITIES
AS DEFINED BY A.S. 47.80.900(7)

	Age Range									
	0-2		3-5		6-20		21+		Total	
Condition	Rate	#	Rate	#	Rate	#	Rate	#	Rate	#
Mental Retardation	.00315	77	.0091	195	.0091	982	.0063	1563	.007	2817
Epilepsy	.0068	166	.00136	29	.00284	307	.0052	1290	.0045	1792
Cerebral Palsy	.002	49	.002	43	.002	216	.001	248	.001	556
Autism	.00045	11	.00045	10	.00045	49	.00045	112	.00045	182
TOTAL	.0124	303	.0129	277	.0144	1554	.0129	3213	.0013	5347

A.S. 47.80 Categorical Definition.

Sources:

U.S. Department of Commerce, Bureau of Census. 1980 Census of Population, General Population Characteristics, Part 3 Alaska. PC80-1-B3 Alaska. Washington, D.C. August 1982. Pp. 3-56, 3-57.

Governor's Council for the Handicapped and Gifted. 1978 Alaska Developmental Disabilities State Plan. Fairbanks, Alaska. August, 1977. Pp. 20, 26.

Functional Limitations of People with Substantial Handicaps

A "substantial functional limitation" is one which prevents a person from performing appropriate activities or which results in the need for significant assistance from other persons or the use of a mechanical device. Such personal assistance or mechanical device either does not compensate for the limitation or, if it does, it is expensive to maintain on an ongoing basis. Significant assistance is assistance which is required for the successful conduct of activities or accomplishment of tasks within the designated major life activities.

- A substantial functional limitation in SELF-CARE is manifest when a person requires significant assistance in performing eating, hygiene, grooming, or health care skills, or when the time required for a person to perform these skills him/herself is extraordinary.
- A substantial functional limitation in RECEPTIVE AND EXPRESSIVE LANGUAGE is manifest when a person is unable to communicate with others, or is unable to communicate effectively without the aide of a third person, a person with special skills, or without a mechanical device.
- A substantial functional limitation in LEARNING is manifest when cognition, retention, reasoning, visual or aural communications, or other learning processes or mechanisms are impaired to the extent that special intervention is required for the development of social, self-care, language, academic or vocational skills.
- A substantial functional limitation in MOBILITY is manifest when fine and/or gross motor skills are impaired to the extent that the assistance of another person or a mechanical device is required for movement from place to place.
- A substantial functional limitation is SELF-DIRECTION is manifest when a person requires assistance in managing his/her self-interest, or making decisions which may affect his/her well-being.
- A substantial functional limitation in CAPACITY FOR INDEPENDENT LIVING is manifest when, for a person's own safety or well-being, supervision or assistance is required, at least on a regular basis, in the performance of health maintenance, housekeeping, budgeting, and leisure time activities and the utilization of community resources.
- A substantial functional limitation in ECONOMIC SELF-SUFFICIENCY is manifest when a person is unable to perform job-related functions necessary for regular employment without special intervention, supervision, or adaptation or modification of the work environment.

A substantially handicapped individual would have limitations in three or more of the above functioning areas. Obviously a variety of different services, specialized personnel, and service delivery modes would be required to meet the needs of this population.

Estimating the number of people with limitations in these major life activities areas is an important part of service planning. Even more difficult is the enumeration of how many people would be limited in any three disability areas. Until data can be obtained from states which have operationalized this functional definition of disability since 1981, the national prevalence rates developed by Boggs and Henney in 1979 (A Numerical and Functional Definition of the Developmentally Disabled Population based on the 1976 Census Survey of Income and Education) will be utilized. Application of these rates to 1980 age-group populations in the seven planning regions is shown in Table 2-8. Estimates for each functional limitation are individually determined and are not mutually exclusive.

TABLE 2-8

PEOPLE WITH FUNCTIONAL LIMITATIONS
AGES 6-64

Region	Self-Care	Rec/Exp. Language	Learning	Mobility	Self-Direction	Individual Living	Economic Self-Sufficiency
North							
6-20	N/A	21	25	6	8	N/A	N/A
21-64	9	27	35	8	14	44	34
Northwest							
6-20	N/A	62	76	19	24	N/A	N/A
21-64	20	63	84	19	32	104	82
Central							
6-20	N/A	290	354	90	113	N/A	N/A
21-64	148	461	614	136	237	762	597
West							
6-20	N/A	91	110	28	35	N/A	N/A
21-64	27	85	113	25	43	140	110
Southwest							
6-20	N/A	29	36	9	12	N/A	N/A
21-64	12	36	48	11	18	59	47
South Central							
6-20	N/A	1,058	1,289	327	411	N/A	N/A
21-64	542	1,685	2,242	498	865	2,785	2,183
Southeast							
6-20	N/A	229	279	71	89	N/A	N/A
21-64	116	362	482	107	186	599	470
TOTAL							
6-20	-	1,780	2,169	550	692	-	-
21-64	874	2,719	3,618	804	1,395	4,493	3,523

Sources: Boggs, Henney. A Numerical and Functional Definition of the Developmentally Disabled Population, 1979. 1976 Survey of Income and Education in the U.S., Census Bureau. 1980 Census.

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Characteristics of the Target Population

Age

The majority of people with substantial handicaps are over the age of 21. Approximately 6% of the population (732 persons) is aged 0-2; 5% of the population (643 persons) is aged 3-5; 26% (2,018 persons) is aged 6-20; 64% (8,020 persons) aged 18-64; and 9% (1,212 persons) aged 65+. The fact that the majority of persons with handicaps are adults is due to the high number of people whose disabilities occur during adulthood. State health planning documents indicate that the primary health status problems for adults aged 25-44 are accidents, alcoholism, veneral disease, and mental/behavioral problems. These problems can lead to a high incidence of substantial handicaps. Additionally, the Council estimates that the vast majority of elderly people aged 65 who are substantially handicapped have these problems as a result of the aging process, not because of developmental disabilities. Studies done for the Older Alaskans Commission indicate that approximately 10% of the elderly population in Alaska are considered substantially disabled.

Geographic Distribution

Approximately 90% of Alaska's population of persons with substantial handicaps live in the more urban areas of Alaska - the southeast, south central and central regions. The remaining 10% are scattered throughout the state. This population distribution by region is displayed in Table 2-8.

Ethnic Composition

As stated earlier, minority groups comprise approximately 23% of Alaska's population. The largest single minority group is the Alaska Native population which comprises approximately 16% of the state's general population. It is not known whether the incidence of substantial handicaps is higher among the Native population than among non-Natives but health data compiled by the health systems agencies and the State Health Planning Agency indicate that the incidence rates for handicapping conditions is higher among Natives because of poor nutrition, and lack of medical care in the "bush" areas of the state where the vast majority of Native people reside.

Poverty

Poverty is discussed in this plan because lack of financial resources is a very real impediment to attaining self-sufficiency and the respect of others. National studies show that people with substantial handicaps are among the poorest groups of people in our country.

- More than 3/4 of the total developmentally disabled population has no previous work experience, compared with less than 1/4 of the remaining population.

- o The average annual income in 1975 of the developmentally disabled population is about one-quarter of the non-disabled population. People with developmental disabilities receive about 67% of their income from public assistance (Aid to the Disabled, Social Security Disability).

- o People with handicaps other than developmental disabilities are only slightly better off financially. The 1975 Survey of Income and Education indicates that people with handicaps from causes other than developmentally disabilities are likely to have an income slightly higher than their developmentally disabled counterparts. Approximately 14% of this population received their primary income from public assistance.

Although statistical figures relating income status and handicapping conditions are not available for Alaska, it is assumed that many of the people with substantial handicaps in Alaska are with incomes near or below poverty level.

Summary and Implications for Planning

Alaska's small population is spread out across a vast land of diverse geography and climate. Yet nearly half the population is located in Anchorage. The push-pull between urban/rural, Anchorage/non-Anchorage for resources and services is great. Widely dispersed rural or bush communities connected only by air make efficient local service delivery a very big need and an even greater challenge.

Sprawling urban areas such as the Kenai and Mat-Su areas are encountering their own difficulties in serving people separated by many road miles. The growth of these sub-regions is accompanied by increased demand and feasibility for local services rather than trips to Anchorage for services.

While this plan uses seven regions to provide sufficient detail and to properly represent the vastness and diversity of the state, there are no uniformly accepted regions used for planning or administration in Alaska. The numerous different regional subdivisions used by the various divisions and departments cause confusion and inefficiency.

A one-third increase in state population from 1970 (300,000) to 1980 (400,000) has created pressure for service development and an atmosphere of "act now, plan later" regarding services has resulted. While Alaska was relatively unburdened by the programs and administrative head-aches of many other states, the imposition of federal programs and the need to develop many services over a very short time span without time to develop necessary infrastructures has caused many problems. Alaska has not been able to do much systematic planning and implementation for the short or long term. Projected high growth rates will continue to make it difficult to design, deliver and fund services adequately.

Diverse cultures and economies have created other pressures. Sometimes cultural traditions have been lost, replaced by dependency and estrangement. While the Alaska native population is 16% of the state population, Alaska natives are over-represented in some service populations. Utilization of program models imported from other states has sometimes been more disruptive than supportive of local resources and traditions.

The juxtaposition of subsistence, non-cash life styles and economies with high cash wages and high cost of living creates another pressure. The transition between subsistence and cash economies poses particular problems for service delivery and makes mobility between rural and urban settings difficult. In addition, subsistence is sometimes equated with economic poverty or lower quality of life.

Socioeconomic factors which affect the incidence of disabilities and the accessibility of services include income and poverty, education, employment substance abuse, domestic violence, and transportation. These factors, singly or in combination, are important determinants of the kinds of lives people with disabilities and their families can expect. The Alaska Maternal-Child Health Plan estimates over 3,000 families headed by women with 37% below poverty guidelines. Eighteen percent of Alaskan families with children are headed by single parents. If families do not have financial resources to pay for air fare and accommodations when medical or specialized services are needed they delay obtaining treatment thus increasing the possibility of permanent disability and long-term dependency.

Education and information levels are related to the likelihood of seeking and obtaining essential care and services. Alcohol abuse has a major influence on families and communities. Fetal alcohol syndrome's life-long effects are just beginning to be detected. Alcohol-related accidents are a major cause of death and disability. Because of the young age of Alaska's population and types of occupations, accidents play a larger part in cause of death or permanent disability than heart disease or cancer. These are discussed and analyzed in the health systems plans.

Alcohol plays a major part in family violence and abuse. Frequency of violence and abuse are higher in Alaska than most of the United States. These factors increase the already high risk of abuse and neglect among disabled children:

> the frequency of physical abuse in low birth weight infants is three times greater than in the general population;
>
> children who are perceived as different or abnormal are more likely to be abused by their parents;
>
> the majority of abuse cases do not involve battering but do involve physical neglect and/or emotional abuse;
>
> stress is a major factor in producing abuse and parents of children with disabilities are predisposed to high stress and abusive behavior;
>
> disabled children may be producers of stress which may lead to their own victimization.
>
> (Child Abuse and Developmental Disabilities Essays, 1980)

The different titles and definitions of handicaps, disabilities, and exceptionalities have served to confuse and intimidate. They sometimes divide and insulate services and consumers rather than promote unity and efficiency. The small numbers of handicapped people in most communities and their similar needs with other population sub-groups comprise a strong rationale for emphasizing flexible generic services and de-emphasizing population categories or labels. The functional federal definition of developmental disabilities helps promote integration of services and comprehensive planning. The "developmental disabilities" label, however, does not. That is why the Council has adopted and added to the federal definition and included a larger population with common characteristics for planning and service delivery.

CHAPTER 3

SERVICES FRAMEWORK

National Context

Federal legislation and national policy affirm the basic rights of people with disabilities. People with disabilities have the same rights other non-disabled citizens have. They are protected by the same constitutional safeguards and are entitled to the benefits provided to other citizens. Additionally Congress has found that special measures need to be taken to safeguard these rights and provide programs to assist people with special needs.

The major federal laws which relate to people with disabilities are listed here. The Guide to Federal Benefits and Programs for Handicapped Citizens and Their Families and Legal Rights of Alaskans with Handicaps explain each law and program in detail.

Architectural Barriers Act of 1968	Requires that public buildings must be accessible to people with physical disabilities.
Vocational Rehabilitation Act, Section 504	States that no qualified handicapped individual shall, on the basis of handicap, be excluded from, be denied the benefits of, or otherwise be subjected to discrimination under any program or activity receiving federal financial assistance.
Education for All Handicapped Children Act of 1975	Provides that all handicapped children shall have available to them a free and appropriate public education which emphasizes special education and related services designed to meet their unique needs.
Social Security Act of 1935, Title V as amended	Provides assistance for medical and related services such as diagnosis and treatment to handicapped children and children with conditions which lead to handicaps; provides maternal and child services.
Title I as amended	Provides old age, survivors, and disability insurance, a program to provide direct cash payments to these individuals.
Title XVI as amended	Provides supplemental security income (SSI) which is a direct cash payment

	program for low-income elderly people, and blind/disabled children or adults whose income and resources are below specified levels.
Title XVIII	Provides protection against many hospital and health care costs for most people who are at least 65 years old and for those disabled people who are under 65 who have been receiving Social Security benefits for at least 24 months.
Title XIX	Provides financial assistance to states to pay for health care services of people receiving federal assistance and of people with low incomes who are unable to meet their family's medical needs. Services such as hospital care, physician's services, early and periodic screening, diagnosis and treatment (EPSDT), skilled nursing facility care (SNF), intermediate care facility services for people with mental retardation and other disabilities. (ICF/MR), psychiatric services, home health care, are included.
Rehabilitation Act of 1973 as amended by P.L. 95-602	Provides vocational rehabilitation services to people with mental and/or physical handicaps (with priority given to people with severe handicaps) to help them prepare for and engage in paid employment.

Other major federal programs which are not necessarily targeted for people with disabilities but may assist such people as part of the general population include: housing programs through Housing and Urban Development and Community Development Block Grants; food and nutrition programs such as child care and school food programs, food stamps; physical and mental health program support such as comprehensive public health services, community mental health centers, income and employment assistance through job service; education and life skills programs such as adult education, community education, vocational education, and head start programs; supportive services such as child protection services, family planning projects, foster grandparent and VISTA programs; transportation assistance through Urban Mass Transportation Assistance (UMTA) programs.

In passing the Developmental Disabilities Assistance and Bill of Rights Act, Public Law 95-602, Congress recognized that these services may tend to overlook or exclude people with developmental disabilities. Congress also found that individuals with disabilities occurring during their developmental period are more vulnerable and less able to reach an independent level of existence than other handicapped individuals who generally have had a normal developmental period on which to draw during the rehabilitative process. Congress recognized that people with these disabilities often require specialized lifelong services which need to be provided by many agencies in a coordinated way. Finally, Congress stated that "it is in the national interest to strengthen specific programs, especially programs that reduce or eliminate the need for institutional care, to meet the needs of persons with developmental disabilities." (P.L. 95-602 Section 101a)

Rather than provide services directly, the federal government has looked to the states to administer programs and provide services. Thus each federal agency usually has some counterpart at the state level.

The Developmental Disabilities Act responds to these findings by assisting states to:

- assure that a comprehensive system of services is available to meet individual needs with priority to people whose needs cannot be covered or otherwise met under the federal programs listed above;
- involve consumers and providers in services planning, implementation, and coordination;
- encourage the establishment of model programs and demonstration of innovative habilitation techniques;
- protect and advocate the legal and human rights of people with disabilities; and,
- improve the capacity of the system to meet special needs.

State Context

In 1977, following a year of preparation and negotiation by the Alaska Developmental Disabilities and Special Education Councils, the Governor introduced House Bill 519 (enacted as A.S. 47.80) to provide a comprehensive legislative framework for meeting the needs of persons with substantial handicaps.

The two planning and advisory groups, broadly representative of public and private groups concerned with services to this population, recognized the need for a strong state law, modeled after the federal laws but adapted to Alaska's specific needs.

Alaska Statute 47.80 merged the two Councils, into the Governor's Council for the Handicapped and Gifted, strengthened its interdepartmental planning responsibilities, enlarged its membership to reflect its broadened scope of representation of people with developmental disabilities and other substantial handicaps, afforded it a strong role in advocating, advising, and monitoring, statewide efforts to meet the needs of this population.

The law also has a bill of rights and a non-discrimination clause similar to Section 504 of the Rehabilitation Act. It establishes a state system to protect and advocate rights of persons with disabilities.

The law establishes a statutory "umbrella" for interdepartmental activities so as to provide a comprehensive system of services. Depending on a person's handicap, different types of services are required for differing needs, and the provisions of the (third) article are intended to assure "that a comprehensive array of services properly provided is available to meet individual needs." (Governor's transmittal letter, Juneau, Alaska, May, 1977)

Requirements for licensure of facilities, certificates of need, individual habilitation plans, program standards and regulations were also included in the law as responsibilities of the Department of Health and Social Services.

Alaska Services Network

The Federal Government authorizes and funds many programs, such as those listed earlier in this chapter, which provide services applicable to the needs of people with disabilities. On the state level these programs are administered by agencies which vary from state to state according to the organization of state government.

Those programs available to the general public and not specifically designed for people with developmental disabilities or other substantial handicaps are called "generic" services. Generic services are the main source of all services. They comprise the first line of resources for people with disabilities and are to be used to the maximum extent possible to meet needs. Most service development activities are targeted for these generic agencies. Special purpose agencies are those specifically established to meet needs which are not presently being met by generic agencies

State programs are briefly summarized here with references made to their federal program counterparts. Which of the federally required services for people with disabilities might be provided by these agencies are listed in parenthesis along with an asterisk for those which are targeted as state priority services by the Council. Also included are the private sector agencies which receive funds from these agencies to provide services.

DEPARTMENT OF EDUCATION

Office for Exceptional Children (Special Education *)	The special education section is one of the education support program sections in the Alaska Department of Education. This office is responsible for the implementation of the Education for All Handicapped Children Act. The section approves local plans of service, conducts program monitoring/auditing to insure compliance, provides technical assistance to the 54 local school districts, develops program standards and regulations, reviews, approves, and funds out-of-district placements, lets contracts for special training and out-reach support services, authorizes disbursement of state special education foundation funds and special federal funds to local districts for the education of handicapped children.
Southeast Regional Resource Center, Juneau (SERRC)	Receives some funds from the Department for training and dissemination activities. Operates the parent training program (SEPTER) in local school districts; contracts with school districts, mostly in Southeast Region, to provide special education support services such as psychological, therapy services, program development.
Alaska Resources for the Moderately and Severely Impaired (ARMSI)	Receives a major contract in excess of $1 million from the Department to provide specialized out-reach services to school districts serving severely handicapped students. ARMSI has five program components which offer training, consultation, materials, and direct instructional services statewide: Blind/Visually Impaired; Emotionally Disturbed; Hearing Impaired; Multi-Handicapped; and Orthopedically Handicapped.
Career and Vocational Education (Vocational Education *)	This section in the Department of Education supports and provides services to people in need of vocational training or education. For school-age students, the Department approves local plans, disburses funds, and monitors programs. For adults,

	the Department operates the Seward Training Center.
Division of Vocational Rehabilitation (Vocational Rehabilitation)	This Division of the Department of Education provides evaluation, testing, job counseling, restoration services, vocational training, maintenance and transportation assistance, and the full range of vocational rehabilitation services to handicapped people.
Alaska Vocational Services Employment and Training Center of Alaska. Fairbanks Rehabilitation Association Gateway Opportunity Center	Private agencies which provide specialized vocational services to developmentally disabled and other handicapped people on a fee for service basis from the Division of Vocational Rehabilitation.

DEPARTMENT OF HEALTH AND SOCIAL SERVICES

Division of Family and Youth Services (protective services, counseling, referral *)	Provides a wide range of social services authorized under Title XX of the Social Security Act: reduce dependency; achieve self sufficiency; prevent or remedy abuse, neglect, or exploitation; prevent or reduce inappropriate institutionalization by providing community-based, home-based, or other care. The Division provides homemaker services and treatment services through contracts. It provides adoption, foster care, counseling, child and adult protective services. It is responsible for licensing and regulating day care, child treatment facilities, and adult residential facilities. The Division has four regional offices and over thirty district offices.
Alaska Management Technologies	Primary statewide private contractor for homemaker training, employment, supervision, and direct provision of homemaker services.
Child Caring Facilities Adult Level I and II Facilities	Private agencies providing residential services which are licensed by and/or receive funds from the Division are

	included in regional chapters according to location.
Division of Public Health (diagnosis, evaluation, treatment, education *) Early Screening Program Family Health Section Child Development Services Home Health Aide Program Health Education Program Infant Learning Program	Under programs authorized by Social Security Act. Provides maternal and child health services, crippled children's services, screening services (EPSDT), well-child clinics, immunizations, family planning, prenatal and postnatal care, and infant learning services. Nursing Section, public health nurses work closely with village health aides who are part of the U.S. Public Health Service which also operates hospitals in several communities. Public Health provides many services directly, such as home health care and public health nursing, but contracts for or provides grants for services such as infant learning and neo-natal intensive care.
Division of Public Assistance (diagnosis, treatment, personal care, domiciliary care)	Provides public assistance grants to individuals, such as OASDI, SSI, and state supplemental funding to recipients on these federal programs under the Social Security Act.
Harborview Developmental Center funding Hope Cottages' ICF/MR funding	This Division also administers funds for nursing home care (SNF, ICF) and facilities for the mentally retarded (ICF/MR) under Title XIX of the Social Security Act.

Division of Mental Health and Developmental Disabilities (personal care, domiciliary care, special living arrangements*, training, sheltered employment, recreation, day care-respite*, counseling*)	Provides in-patient, out-patient, day-care, care, partial hospitalization, emergency services, consultation and education services, assistance to courts and other public agencies, follow-up care, transitional halfway house services as part of comprehensive mental health services for children and adults.
Mental Health Section	
Community Mental Health Centers	Private agencies provide community mental health services under grants from the Division.
Alaska Psychiatric Institute	The state's in-patient psychiatric facility operated by the Division.
Developmental Disabilities Section	Serves as a back-up agency to a portion of the state's generic services. That portion includes severely mentally handicapped individuals who are included within the larger target population of people with substantial disabilities. The DD Section provides a significant range of services which are not provided or not adequately provided by other state programs.
Fairbanks Rehabilitation Association Hope Cottages REACH CHILD Gateway Opportunity Center Ketchikan KAPPS Sitka PACS Bethel Social Services Kenai Mental Health Center Kodiak Mental Health Center Employment and Training Center of Alaska Protection and Advocacy for the Developmentally Disabled St. Jude Center Satellite Home Program Adult Learning Programs of Alaska Juneau Association for Retarded Citizens	Private organizations provide community services under contracts with the Division. Agencies are described in the regional chapters of the plan according to their geographic location.
Harborview Developmental Center	The state's institution for people with developmental disabilities operated by the Division.

DEPARTMENT OF COMMUNITY AND REGIONAL AFFAIRS

Local Government Assistance Division (Day care and education *)	Administers the day care assistance program through local governments and private day care homes and centers.
Housing Assistance Division	Administers programs which provide financing for home purchases and construction of senior citizen rental housing; provides information and assistance to individuals and financial institutions concerning all state loan programs.
Community Planning Division	Responsible for providing planning assistance to local governments and completing special studies such as the statewide housing needs study. Administers HUD 701 funds allocated to Alaska.
Community Employment and Training Assistance Division	Administers the federal Comprehensive Employment and Training Act and its successor program, under the Job Training Partnership Act.

ALASKA COURT SYSTEM

Office of Public Guardian (protective and socio-legal services)	Provides information and assistance on guardianship; serves as a partial or full guardian or conservator for people who do not have family, friends, or other people willing or able to act in their behalf.

DEPARTMENT OF COMMERCE AND ECONOMIC DEVELOPMENT

Division of Business Loans	Administers the child care facilities revolving loan fund and the residential care facility revolving loan fund (A.S. 44.33).

DEPARTMENT OF LABOR

Department of Labor	Provides job service and employment referral services; operates the Work Incentive Program (WIN) and the Youth Employment Services (YES).

DEPARTMENT OF TRANSPORTATION AND PUBLIC FACILITIES

Design and Construction Facilities Planning and Research	Responsible for design and construction, and planning of state buildings, airports, schools, highways, and marine vessels in conformance with accessibility standards.

Service Philosophy

The principle of "normalization" forms the underlying philosophy on which service goals and activities prescribed in the plan are based and against which current services and service systems are measured.

The concept of normalization was developed by program specialists in Scandinavian countries in the 1950's. It was systematically described in 1969 by Bengt Nirje, Executive Director of the Swedish Association for the Mentally Retarded, as follows:

> "making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society."

While the principle was developed in response to concerns about the design and operation of residential facilities for the mentally retarded, the relevance of the principle beyond residential services and beyond mental retardation to all services and service populations and human management in general, became widely recognized.

The principle was reformulated in the United States and Canada in 1972 by Wolf Wolfensberger for general applicability to human services management and state as follows:

> "utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible."

Formulation of the principle of normalization and repeated mention and discussion of its implications is necessitated by the need to clarify and make conscious our attitudes and values regarding persons or groups of persons, such as handicapped or developmentally disabled persons, who are perceived as being significantly different from others in some aspect that is considered important, and because of that perceived difference being negatively valued or seen as a 'stigma'.

"The normalization principle as stated is deceptively simple. Many individuals will agree to it wholeheartedly while lacking awareness of even the most immediate and major corollaries and implications. Indeed, many human managers endorse the principle readily while engaging in practices quite opposed to it-without being aware of this discordance until the implications are spelled out. Then a manager may find himself in a very painful dilemma, endorsing simultaneously a principle, as well as practices opposed to it." (Wolfensberger, The Principle of Normalization in Human Services, National Institute of Mental Retardation, 1972, p. 29.)

The Council and provider agencies have endorsed the principle of normalization as the basis for development of service standards by generic agencies in proposed regulations developed for A.S. 47.80. The proposed state regulations define "normalization":

> "helping individuals with handicaps learn, develop, establish, and maintain personal behaviors and characteristics which are as close as possible to the norms and patterns of the mainstream of society by providing services in community environments which reflect and make available patterns and conditions of everyday life, including opportunities to engage in activities in the same environments and interact with individuals who do not have handicaps".

Major corollaries and implications of the principle of normalization for services to handicapped and developmentally disabled persons are as follows:

- maximal integration into the societal mainstream

  obtain/provide services from generic agencies which serve the general public, rather than from specialty agencies which serve only or primarily handicapped or developmentally disabled persons

- physical integration of services and people

  location at the community level so that persons may remain in or be absorbed into the prevailing social, economic, and/or educational systems

  physical context consistent with the type of service to be provided, e.g. vocational services in industrial, commercial or business areas, residences in residential areas

  access to and from other services and community resources determined by distance, availability, and convenience of transportation

  size/dispersal in communities and neighborhoods so as not to congregate groups of individuals in numbers larger than the community can absorb, integrate, and individualize;

instead of single large facilities, a number of small facilities usually permit greater dispersal within and between population centers; services should be dispersed across the state, region, or community consistent with population patterns, and located so as to enable all individuals to take full advantage of other existing community resources

- social integration of services and people

  program features affording social interaction with non-handicapped persons; e.g. handicapped children should be integrated into community day care centers; vocational training should take place in community businesses and industries rather than in sheltered workshops; transportation services should utilize public buses or car pools rather than special segregated buses

  labelling that promotes a positive role perception of people served and the settings and facilities in which the services are provided

  building perception which promotes community acceptance and integration of service facilities determined by architecture, appearance, size, condition, and previous uses of the buildings

Service Principles

The service principles specifically included in A.S. 47.80 are consistent with federal developmental disabilities and special education legislation and the principle of normalization.

1. Services for persons with handicaps or developmental disabilities should be specialized or specially adapted services which are available to the general public;
2. Services should be provided by the generic agencies which provide such services or similar services to the general population;
3. Services must be designated to maximize individual potential;
4. Services must be designed to minimize institutionalization;
5. Services must be provided in the last restrictive setting, enabling a person to live as normally as possible;
6. Services must be dispersed geographically within the state.

Service Planning Construct

To apply the philosophy of normalization and accompanying service principles to the planning and delivery of services, the Council developed a Services Planning Construct in 1979.

A handicap is a condition which hinders a person's ability to engage in the same activities as his or her peers.

Persons with handicaps may need special assistance in order to engage in these activities. Assistance may involve special training, modifications of the physical environment, medical care and treatment, or help in overcoming attitudinal barriers, medical care and treatment, or help in overcoming attitudinal barriers which reduce opportunities for full community participation. Such assistance constitutes service.

Services can be categorized according to the time of day or week at which they are utilized and according to the environment in which they are provided.

Time of Day

Services should be designed to provide supports and options in groupings which follow the natural rhythm of the day and week. Services can be categorized by the time of day or week at which they are utilized. In our culture activities are clustered in a day (work, training), evening and week-end (leisure, recreation) and overnight (residential) framework. Depending on a person's age, a person is expected to engage in certain types of activities during these time periods. Children are expected to go to school during the day, play or participate in recreation activities evenings and weekends, and spend the night with their families in the family home or apartment. Similarly, adults ordinarily work during the day, engage in social or recreational activities during the evening or week-end, and spend the night in their own homes or apartments.

Environment

Services should be designed to take place in environments which support and promote social and physical integration in the community. Services must support, not supplant, typical community environments and the resources and capabilities of families and family networks (relatives, friends, neighbors). A continuum of environments in which a handicapped person may participate in activities is presented below:

ENVIRONMENTS

Least Restrictive		Moderately Restrictive	Most Restrictive
Natural	Augmented	Devised	Protective

Least Restrictive Environments

The least restrictive environments in which services can be delivered are "natural" or "augmented" settings in the community. For education, the natural environment is the local school; for work it is job sites in the community; for medical care it is the local clinic; for residence it is the family home.

"Augmented environments" are natural environments to which adaptation or additions have been made. Examples are teachers aides in regular classrooms, on-the-job training in competitive employment, homemaker, home health aide, respite care in the family home. Services are usually provided by aides or specialists who serve the handicapped person in "natural" settings.

The Services Planning Construct assumes that all services goals can be achieved in the natural or augmented environments if the necessary support and specialized services are provided in the local area. To achieve services goals in the natural or augmented setting, it follows that support and specialized services must be designed so that they are available regardless of placement in other settings. In other words, a person with a handicap who needs physical therapy, speech therapy, or orientation and mobility training should not be required to move from the family home to a special overnight setting as a condition for receipt of service.

While natural or augmented environments are generally viewed as most desirable in that they provide the greatest possibility for social and physical integration and personal continuity, there are specific instances in which such settings lack the necessary resources to promote individual growth and development even when active support is provided. In such cases, services in devised environments may be more appropriate.

Moderately Restrictive Environments

Moderately restrictive environments are community settings which are specially created to serve particular groups of people and usually control their activities only one part of the day. Such "devised" settings are group homes, day care or resite care centers for handicapped children, self-contained special education classrooms, or sheltered workshops. The Services Planning Construct assumes that all service goals can be achieved in moderately restrictive settings.

Most Restrictive Environments

The most restrictive environments are special settings established specifically for handicapped persons which are isolated from typical settings in which non-handicapped persons engage in activities. Such "protective" environments shelter a group of unrelated handicapped persons in one setting and often control their activities twenty-four hours a day. Protective environments are hospitals, nursing homes, institutions or special schools for the handicapped which are used for residential care and also for day-time and evening activities. The Services Planning Construct assumes that protective settings are appropriate environments for services to handicapped or developmentally disabled persons whose behavior poses a danger to self or others and for those who require intensive and continuous medical care.

Tables 3-16 and 3-17 illustrate the planning concepts described above. They take age normative services and activities, divide them into the times of day at which they occur, and then illustrate environments in which services and activities can take place.

Planning Construct Summary

A balanced service system provides a range of services and options in natural, augmented, and devised environments so that families and people with handicaps may select those options which best meet their service needs and purposes.

Planning for services should follow this framework:

- The handicapped person and his or her family and the local community are the center of the service system.
- Individual and group needs should be identified according to the day-evening-overnight framework giving first consideration to daytime services, then evenings, and then overnight services.
- Service activities should be defined in terms of the least restrictive setting possible, giving first consideration to activities which support the handicapped person in natural and augmented environments. Rationale must be provided as to why services cannot be provided in these least restrictive settings before devised environments are considered.
- The existing resources of generic agencies should be identified and assessed. These agencies should be actively encouraged to adapt or specialize service components for access by handicapped persons and their families. Only after generic resources are utilized to develop a wide range of community-based services should specialized service agencies be developed to provide back up services for those people excluded from generic services.
- Protective environments are considered last and only when a person needs to be separated from the community because of medical needs or when a person's behavior poses a danger to self or others.

TABLE 3-16

SERVICE ENVIRONMENTS FOR CHILDREN WITH HANDICAPS

	Least Restrictive			Most Restrictive
	NATURAL ENVIRONMENT	AUGMENTED ENVIRONMENT	DEVISED ENVIRONMENT	PROTECTIVE ENVIRONMENT
DAY	School	Regular classroom with special aid	Special class in regular school building	Special school for the handicapped
EVENING	At home or community recreational activities	Community recreation programs with assistance	Community facilities at special times and in supervised activities with handicapped people	Separate recreational facility and activities for handicapped people
OVERNIGHT	At home	At foster home some nights; at home the rest of the time	Specialized foster care; group home care	Institution or Nursing home
SUPPORT	Health insurance Day care Baby sitter	Family subsidy Respite care or homemaker service in own home; Specially trained baby sitter	Day care center for handicapped children; Respite care out of home or family setting	Day care or respite care in an institution or hospital

TABLE 3-17

SERVICE ENVIRONMENTS FOR ADULTS WITH HANDICAPS

	Least Restrictive			Most Restrictive
	NATURAL ENVIRONMENT	AUGMENTED ENVIRONMENT	DEVISED ENVIRONMENT	PROTECTIVE ENVIRONMENT
DAY	Works in competitive job in community or attends school	Works in competitive job with special aids installed, or employment is subsidized (OJT)	Works at competitive job for less than normal wage or at specially created job station; works at sheltered workshop in community setting	Works at Sheltered workshop in an institution, nursing home or hospital
EVENING	Uses public events and facilities for recreation and social activities	Uses public events and facilities with assistance; transportation or accompanied by specially arranged person	Attends special recreation and social activities for the handicapped in public community facilities	Attends recreation and social activities for the handicapped in an institution, nursing home or facility for the handicapped
OVERNIGHT	Lives on own in home or apartment	Lives on own with occasional visits or supervision by an agency person	Lives in supervised apartment or group home	Lives in institution, medical facility or nursing home
SUPPORT	Insurance-Workmen's Compensation, Unemployment Uses public transportation	National insurance or tax breaks for handicapped; SSI aid to disabled Uses public transportation with special assistance	Uses specially provided transportation for the handicapped	Uses institution bus with special aids and personal supervision

The philosophy of normalization, the state's service principles, and the services planning construct formally recognize the individual, his or her family, and the community as the center of the service system. It recognizes that all individuals have the capacity to learn, grow, and develop if adequate assistance is provided. It maintains that service outcomes tend to improve when services are provided in natural community settings where those served are expected to function as members of the community. It recognizes that community integration is an appropriate and accepted service goal.

Desirable service systems founded on these philosophies and principles would:

- meet individual needs
- allow people to make their own choices
- have financial independence;
  - meet needs with own resources,
  - provide encough funding for services
- respect and foster individual differences
- have systems work and be coordinated;
  - teamwork
- have a community of caring people to support people in need
- have persons taking personal responsibility
- result in an aware public
- use and result in sharing of talents, ideas, services, decisions, and consequences
- result in active participation in the village or community (Improving Home and Family Support: Search Conference, Fairbanks, 1982).

LEVELS OF CARE CONCEPT

Organization

Over the past ten years, the Alaska statewide health planning network has devoted considerable effort to the development of appropriate service descriptions and linkages between communities and service providers which are essential for comprehensive health care delivery in a state as internally diverse as Alaska. Because of the close association between health care needs of the general public and health care needs of the handicapped, the Governor's Council for the Handicapped and Gifted reviewed the "levels of care" concept in use by the Health Systems Agencies and the Statewide Health Coordinating Council and chose to adopt the same planning approach in its statewide planning efforts for the disabled. The Governor's Council has added services especially appropriate for the disabled to the guidelines for recommended resources.

Organization of the Alaska health care system utilizes a regional approach, with types of health services established for each community level. These levels are defined as:

Level I	Village
Level II	Subregional Center
Level III	Regional Center
Level IV	Urban Center
Level V	Metropolis
Other	Usually community clusters, military bases, worksites, and schools

The resources (services, personnel, and facilities) identified for each of the five levels are recommended as "Guidelines" in this plan. However, specific resources to be provided in any individual community should be determined on the basis of need. Characteristics to be considered include:

1. Demographic factors (population size, age, etc.)
2. Health status of the population.
3. Anticipated frequency that the service will be required.
4. Economic feasibility of providing the service.

Regardless of the level classification within which a community may be designated, economic realities do not permit provision of every recommended service in each community. Compromises must be made with respect to time and distance from other communities, as well as to the overall scope of services available within a given community. The levels of care concept encompasses the elements of continuity, coordination, and an array of services. Transportation, communication, and client/consumer needs will often determine service and referral patterns. The guidelines for recommended resources must be viewed as just that -- guidelines, or suggested service delivery arrays, which are appropriate for given levels of communities. These guidelines are not intended to be minimums which each community must strive to provide for its residents. Rather, they are generally the maximum range of services which are economically feasible and which will allow maintenance of technical skills on the part of service personnel.

One aspect of the Alaskan levels of care criteria which makes them unusual is that they are based on the premise that communities are linked together and are mutually dependent for comprehensive service delivery. The general "flow" of services is from Level I communities to Level IIs and so on to Level V cities. Each higher level community provides support services to its surrounding small communities. These support services often include itinerant services, administrative services, and more sophisticated or specialized services than are feasible or practical in smaller places.

For parts of the state where communities are linked by roads, the idea of "community clusters" has been developed. Under this concept, communities in close proximity are considered together for purposes of planning for service development. Towns and villages which are considered to be closely tied with larger, subregional centers are called "adjacent" communities, with the center called the "hub" community. Clusters are particularly common on the South Central Region, although they are also found elsewhere. An example is Homer, a Level III community which serves as the hub city for the cluster including Anchor Point, Fritz Creek, Kachemak, and Nikolaevsk. Glennallen is another hub community, serving the adjacent cluster communities of Copper Center, Gakona, Gulkana, Paxson, Tazlina, and Tonsina. Some clusters are much smaller, sometimes involving only two communities, such as Cordova and Eyak.

Level I Community -- Village

Level I communities range in size from 25 to 750 people in the immediate vicinity, although most of them are considerably smaller than 750. They are usually more than thirty minutes away from a high level community by year-round surface transportation. Services available in these communities are confined to primary care, which consists of the most commonly needed types of care. Appropriate services for Level I communities generally meet one or more of the following criteria:

1. They are services needed on an ongoing basis that can be conveniently provided in small communities.
2. They are designed primarily for ambulatory/outpatient care.
3. They are emergency services which must be provided in a timely manner.

Primary care in Level I communities includes the range of services that provide adequately for most of the daily personal health care needs of the population. It encompasses preventive health maintenance and education; continuing evaluation and management of conditions of general discomfort; early identification and treatment of common problems; and, management of chronic conditions. The main characteristic of primary care provided in villages is that it is non-intensive, low-specialization care. In itself, primary care does not provide total or comprehensive services. As the entry and continuity point for comprehensive care, however, it has a unique potential for becoming the key element in a comprehensive community system.

Level II Community -- Subregional Center

Level II communities range in size from 500 to 2,500 people in the immediate community, or a service area population of at least 1,000. These communities generally lie within thirty minutes access time to outlying villages and are more than thirty minutes by year-round surface transportation from another Level II or higher level community. They often serve as transportation hubs for surrounding villages and are linked by air to a Level III or IV community.

Level II communities also have primary care services, though they usually offer a broader range of services than those provided in Level I communities. These additional services include those that must be reasonably close to consumers to assure availability, accessibility, and use as needed and appropriate. Often, subregional centers serve as home bases for itinerant nurses and other personnel. They also frequently offer behavioral health services unavailable in Level I communities.

Level III Communities -- Regional Center

Level III communities have 1,500 to 60,000 people in their immediate areas and more than 3,000 in their primary service areas. The regional center should be within sixty minutes travel time for at least 90% of the population in the primary service area but more than thirty minutes by year-round surface transportation from a community providing equivalent or higher level services. Regional centers function as hubs for maintenance services, commodities, financial services, and transportation to Level I and II communities within their primary service areas.

Level III communities provide expanded services which include basic hospital and inpatient care, including diagnostic workups, routine laboratory services, provision of services for normal obstetrical cases, general surgery as appropriate, and other episodic care. These centers also offer day care, boarding home services, speech and hearing services, occupational and physical therapy, and vocational training. They provide itinerant services to small communities and receive specialized itinerant services, such as cardiac or orthopedic clinics.

Level IV Community -- Urban Center

Anchorage and Fairbanks are the only Level IV communities in Alaska. To be classified as a Level IV, communities must have 40,000 - 750,000 population in their immediate vicinity. They must provide daily scheduled transportation services to Level III communities and to the closest Level V community (Seattle). Urban centers function as commercial services hubs for speciality human services and for commodities and communications networks.

Level IV communities have a larger range and scope of services than any other type of population center in Alaska. Many of these services should not be decentralized because of the relatively small demand for them or because of the expense and sophisticated skills required to operate them. These services tend to be institutionally related, although they may not be located together physically. Certain recognized centers for specialized services, such as thermal injury, head and spinal injury, high-risk neonatal care, and open heart surgery, require a significant population base to justify their establishment and maintenance. The economic viability of some of these services and the provision and maintenance of clinical expertise and technology are largely dependent on an appropriate population base which may not exist even within Alaska. In those cases, Alaskan patients are referred to communities outside the state.

Level V Community -- Metropolis

Level V communities have populations in excess of 450,000, with highly sophisticated commercial and service industries. Currently, there are no Level V communities in Alaska. The closest Level V community is Seattle, which is often seen as the speciality service center for medical and rehabilitation services for Alaskan residents. Services provided only in Level V communities are highly advanced specialist and technological care which deals with problems of low incidence in the general population. Alaska's population currently does not justify the expense of providing this type of care, nor would a sufficient caseload be available to maintain the technical proficiency of the staff. Economics and quality thus warrant exclusion of these services from Alaska for the time being. Examples of these services are organ transplants, complex pediatric heart surgery, and major burn care and rehabilitation.

Other Settings

There are several types of "communities" which do not fit easily within the levels of care described above. Some of these settings include community clusters, which are group of communities on all-weather roads within twenty miles of each other but more than thirty miles from a larger community; highway communities, which are series of communities on all-weather roads which are within thirty miles of larger communities; schools; high-risk occupational groups; self-contained military reservations; and, isolated communities with fewer than 25 residents. Services appropriate for these settings must be determined according to their individual locations, needs, and priorities.

Guidelines for Recommended Resources

The following "Guidelines for Recommended Resources" contain all of the services which the Governor's Council for the Handicapped and Gifted deems appropriate and necessary for disabled individuals. Some of these services were previously included in the health planning network's Guidelines; others are new additions prepared by the Governor's Council especially for the disabled. Asterisks identify the new services which the Governor's Council has proposed and which the Northern Alaska Health Resources Association has agreed to incorporate into the statewide Guidelines for Recommended Resources for use by the health planning agencies. A complete set of the Guidelines, including both the original health care resources and the new resources for the handicapped, is contained in the Appendix.

HEALTH SERVICES

GUIDELINES FOR RECOMMENDED RESOURCES

Service	Level of Community I	II	III	IV
Prenatal Care	L	L	L	L
School Health Curriculum	L	L	L	L
Public Awareness Activities			L	L
Well-Child Programs	I	L	L	L
Immunizations	I	L	L	L
Prenatal Testing				L
Medical/Developmental Screening	L	L	L	L
Metabolic Screening			L	L
Genetic Counselling				I
Diagnosis and Evaluation of Handicapping Conditions		L	L	L
Medical Services	I	I	L	L
Dental Services	I	I	L	L
Occupational Therapy	I	I	L	L
Physical Therapy	I	I	L	L
Speech and Hearing Services	I	L	L	L
Home Health Aide Services	L	L	L	L
Home Health Nursing			L	L
Genetic Counseling			I	I

L = Locally Available; I = Itinerant Service

Source: Alaska Governor's Council for the Handicapped and Gifted, 1983.

SUPPORT SERVICES

GUIDELINES FOR RECOMMENDED RESOURCES

	Level of Community			
Service	I	II	III	IV
MAINTENANCE SERVICES				
Day Care Home/Sitter/Specialized Sitter (Respite Care)	L	L	L	L
Day Care Center			L	L
Homemaker	L	L	L	L
Personal Aides and Attendants			L	L
Transportation	L	L	L	L
Recreation	L	L	L	L
DEVELOPMENTAL SERVICES				
Family Counseling and Training	I	L	L	L
Individual Counseling	I	L	L	L
Personal and Social Skills Development	L	L	L	L
Independent Living Skills Training	L	L	L	L
MATERIAL SUPPORT SERVICES				
Financial Assistance	L	L	L	L
Environmental Adaptive Equipment	L	L	L	L

L = Locally Available; I = Itinerant Service

Source: Alaska Governor's Council for the Handicapped and Gifted, 1983.

RESIDENTIAL OPTIONS

GUIDELINES FOR RECOMMENDED RESOURCES

Service	Level of Community I	II	III	IV
OPTIONS IN THE NATURAL/ AUGMENTED ENVIRONMENT				
Family or Own Home	L	L	L	L
Foster Care	L	L	L	L
Adoption	L	L	L	L
Subsidized Adoption	L	L	L	L
Specialized Foster Care	L	L	L	L
Semi-Independent Living Environments for Adults	L	L	L	L
OPTIONS IN THE DEVISED ENVIRONMENT				
Group Homes		L	L	L
Boarding Homes			L	L
Safe Houses	L	L	L	L
Receiving Homes			L	L
Women's Shelters			L	L
Emergency Housing			L	L
OPTIONS IN THE PROTECTIVE ENVIRONMENT				
Residential Treatment Centers			L	L
Nursing Homes			L	L
Correctional Facilities				L

L = Locally Available

Source: Alaska Governor's Council for the Handicapped and Gifted, 1983.

EDUCATIONAL SERVICES

GUIDELINES FOR RECOMMENDED RESOURCES

Service	Level of Community			
	I	II	III	IV
Infant Learning Programs	I	L	L	L
Pre-School Programs	L	L	L	L
Special Education				
Regular Classroom	L	L	L	L
Regular Classroom with Supplements	L	L	L	L
Regular Classroom with Resource Room	L	L	L	L
Self-contained class or resource room			L	L
Special Education Day School				L
Residential School				L
Hospital, Treatment Center, Correctional Facility			L	L
Home-Bound or Correspondence Study	L	L	L	L
Related Education Services				
Transportation	L	L	L	L
Speech Pathology and Audiology	I	I	L	L
Psychological Services	I	I	L	L
Physical and Occupational Therapy	I	I	L	L
Recreation	L	L	L	L
Early Identification and Assessment	L	L	L	L
Diagnostic and Evaluative Medical Services	I	I	L	L
Counseling Services	L	L	L	L
School Health Services	L	L	L	L
Social Work Services			L	L
Parent Counseling and Training	L	L	L	L
Post-Secondary and Adult Education Services		L	L	L

L = Locally Available; I = Itinerant Service

Source: Alaska's Governor's Council for the Handicapped and Gifted, 1983.

VOCATIONAL SERVICES

GUIDELINES FOR RECOMMENDED RESOURCES

	Level of Community			
Service	*I*	*II*	*III*	*IV*
Career and Vocational Education	L	L	L	L
Vocational Evaluation			L	L
Pre-Vocational Training	L	L	L	L
Vocational Counseling	I	L	L	L
Vocational Training			L	L
Vocational Placement			L	L
Vocational Follow-Along			L	L

L = Locally Available; I = Itinerant Service

Source: Alaska's Governor's Council for the Handicapped and Gifted, 1983.

ENABLING SERVICES

GUIDELINES FOR RECOMMENDED RESOURCES

	Level of Community			
Service	*I*	*II*	*III*	*IV*
Case Management	I	I	L	L
Guardianship	L	L	L	L
Staff training/manpower development	L	L	L	L
Information and Referral	L	L	L	L
Protection and Advocacy	I	I	L	L

L = Locally Available; I = Itinerant Service

Source: Alaska's Governor's Council for the Handicapped and Gifted, 1983.

LEVEL I

GUIDELINES FOR RECOMMENDED RESOURCES

Services	Personnel	Facilities
Resident		
Health Services		
Health Promotion	Community Health Aide	Health Clinic:
Education, Counseling	Alternate Health Aide	-- electricity;
Early Detection		-- water;
Information, Referral		-- heat.
Prevention/Alternative Activities		
Diagnostic Screening		
Primary Acute Care		
Limited pharmacy		
Outreach		-- private examining;
		-- secure storage;
After care/support	Behavior Health Worker	-- reliable communications link to a referral center (radio and/or telephone).
Law Enforcement, as needed	Village Public Safety Officer as needed	
Emergency sleep-off (detox)		Recreational/social health center (school facility)
Foster Care		
Basic Life Support	EMT-1 EMT-Bush	
*School health education	*Teacher/teacher assistant	*School
*Vision and hearing screening		
*Home Health Aide services	*Home Health aide	
Support Services		
*Day care homes/sitter/specialized sitter (respite) services	*Sitter/Day Care worker	
Homemaker services	Homemaker	
*Transportation		
*Recreation		
*Developmental services	*Parent aides/Community service aides	
- Counseling and training (for family and individual)		
- Personal and social skills training		
- Independent living (survival) skills training		
*Material support services		*Adaptable or accessible housing
- Financial assistance		
- Environmental adaptive equipment		
- Personal adaptive equipment		
*Family		
Foster Care	Foster parents	
*Adoption	*Adoptive families	
*Subsidized adoption		
*Specialized foster care		*Semi-independent living settings (homes, apartments)
*Semi-independent living for adults		*Safehouses
*Safe houses		
Educational Services		
*Pre-school program		
*Special education		
- Regular classroom		
- Regular classroom with supplements		
- Regular classroom with resource room		
- Homebound or correspondence study		
*Related Services		
- Transportation		
- Recreation		
- Counseling services		
- School health services		
- Parent counseling and training		
***Vocational Services**		
*Career and vocational education		
*Pre-vocational training		
Enabling Services		
Guardianship		
Staff training/manpower development		
Information and referral		

(Continued on page 3-29)

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LEVEL I — 25-75 people

GUIDELINES FOR RECOMMENDED RESOURCES
(Continue from page 3-28)

Services	Personnel	Facilities
Itinerant		
Screening	Public Health Nurse	
Primary Care & Follow-up		
Family Planning		
Prenatal Care		
Well-child Care		
*Immunizations		
Dental	Health Specialists	
Eye		
Audiology		
Environmental Sanitation		
Behavioral Health	Behavioral Health Worker	
*Educational Assessment	*Education specialists	
*Occupational therapy	*Occupational therapist	
*Physical therapy	*Physical therapist	
*Speech services	*Speech and hearing specialist	
*Vocational counseling	*Infant learning teacher or aide	
*Case management	*Vocational Rehabilitation counselor	
*Protection and advocacy		

*Indicates additions or changes proposed by the Governor's Council for the Handicapped and Gifted.

LEVEL II -500-2500 people

GUIDELINES FOR RECOMMENDED RESOURCES

Services	Personnel	Facilities
Locally-Based		
Same as in Level I communities, plus the following:		
Health Services		
Preventive health care (including immunizations, family planning, well-child care, and prenatal care)	Health educator	*Short-term residential/halfway house
*Diagnosis and evaluation of handicapping conditions	*Health and Education Specialists	*Group Home
Support Services		
*Nutrition services		
Residential Options		
Short-term residential/halfway house *Group homes (5 or less people)	*Residential services staff	
Educational Services		
*Infant Learning	*Infant Learning teacher/or aide	
Itinerant Services		
Same as in Level I communities.		

*Indicates additions or changes proposed by the Governor's Council for the Handicapped and Gifted

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LEVEL III

GUIDELINES FOR RECOMMENDED RESOURCES

1,500 - 60,000 people

Services	Personnel	Facilities
Locally-Based		
Same as in Level II communities, plus the following:		
Health Services		
*Public awareness on the causes of handicapping conditions		
*Genetic counseling		
*Metabolic screening	Social Worker	
*Speech and hearing services	*Speech and hearing specialist	
*Occupational therapy	*Occupational therapist	
*Physical therapy	*Physical therapist	
Inpatient psychiatric treatment		
Home health nursing	*Home health nurse	
Support Services		
*Day care center	*Early childhood specialists	*Day care centers
*Personal aides and attendants	*Personal aides and attendants	
Community-based mental health/rehab.	Psychologists, social workers	
Residential Options		
*Boarding home		*Boarding home
*Residential treatment center	*Residential services staff	*Homes and small dispersed group residential facilities
Nursing home		Nursing home or long term care beds associated with the hospital
Chronic care and long-term residential services		
Short-term shelter		
*Emergency housing		
Educational Services		
Resource rooms		
*Vocational Services		
*Vocational evaluation	*Vocational specialists	*Vocational center (may be in the school)
*Vocational training		
*Vocational placement		
*Vocational follow-along		
Enabling Services		
Case management		
Protection and advocacy		
*Itinerant		
*Specialized clinics (e.g., genetic, cardiac, orthopedic)	*Medical specialists	
*Educational consulting services		

*Indicates additions or changes proposed by the Governor's Council for the Handicapped and Gifted

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LEVEL IV

40,000-275,000

GUIDELINES FOR RECOMMENDED RESOURCES

Services	Personnel	Facilities
Locally-Based		
Same as in Level III communities, plus the following:		
Health Services		
*Prenatal testing Major diagnostic services Ophthalmic services Basic rehabilitation	*Medical, vocational, education and ancillary personnel in residence to ensure quality provision of appropriate services	*The types of facilities necessary will depend on the population and need configurations of each Level IV community and its service area.
*Residential Options		
*Correctional facility		
Enabling Services		
*Staff training and manpower development services *Protection and advocacy services *Guardianship services		

*Indicates additions or changes proposed by the Governor's Council for the Handicapped and Gifted.

CHAPTER 4

AN OVERVIEW OF SERVICES

Introduction

This chapter identifies and discusses each of the services which may be needed by persons with substantial handicaps and their families. The chapter is organized into six parts:

1. Health Services.
2. Support Services.
3. Residential Services.
4. Educational Services.
5. Vocational Services.
6. Enabling Services.

For each group, definitions of the discrete service components are presented. Additionally, each service component is discussed in terms of current services available in Alaska.

Health Services

Health services include the prevention, early identification, diagnosis, evaluation, and treatment of medical conditions which can lead to substantial handicaps. This plan deals in depth with only a few of the "Health Services" indicated for various levels of communities. People with substantial handicaps will need many of the same health services as the general population. However, certain services are particularly needed by people with handicaps and their families. Those services are as follows:

Health services in Alaska are provided through five major delivery systems: private practice medicine, Alaska Area Native Health Service (AANHS) under U.S. Public Health Service for Alaska Natives, Regional Health Corporations for community health aides, the State Division of Public Health for direct and contract services, and the military health service.

Prevention Services

Genetic Counseling

Genetic counseling is the information that people receive from a medical authority with regard to the possibilities that a child born to them might have some genetic condition that could lead to a handicap. Generally, any one thinking about having children should consider his/her need for genetic counseling. People who should especially consider seeking this service include women over the age of 35, families who already have a handicapped child, women who have a history of miscarriages, and families who have a family history of handicapping conditions.

A variety of professionals provide genetic counseling in a number of ways. The personal physician or public health nurse who regularly sees the individual or family sometimes gives initial information. This professional can give advice about the need for further counseling and evaluation. Genetics and birth defects clinics are offered on an itinerant basis in six Alaskan communities in conjunction with the March of Dimes, the University of Washington and medical health professionals in Alaska; this type of genetic counselling can range from advice-giving to interpretation of genetic tests.

Prenatal Care

Prenatal care leads to the bearing of normal, healthy children. According to the state Maternal and Child Health Plan, important components include: 1) proper nutrition; 2) avoidance of hazards known to affect fetal development such as tobacco, sedatives, and certain other drugs; 3) health education; and, 4) early and periodic health examinations to detect and treat any disease of the mother or fetus.

Medical experts advise all women to seek medical help as soon as they suspect they are pregnant, but certainly not later than the end of the first three months of pregnancy.

In Alaska, prenatal care is provided by a number of different health professionals depending on the size of the community and location. Women in villages and subregional centers generally receive primary prenatal care from the local community health aide, public health nurse, or physician's assistant. In the regional and urban centers, care is generally provided by a family physician or obstetrician. Ninety-eight percent of the births in Alaska occur in hospitals. Typical practice for women in the bush is to travel to the nearest Alaska Area Native Health Service hospital; non-Native women in the urban areas usually travel to community or private hospitals. Military dependents seek delivery services at military hospitals or in the private sector. There is a recent trend for regional centers to provide a hostel to house pregnant women in their final weeks of pregnancy so that they can be near hospital obstetrical services.

School Health Curriculum

A school health curriculum offers a wide range of health-related information to children enrolled in school. According to national research, of particular importance to the prevention of handicapping conditions is the inclusion in this curriculum of information and instruction on the causes of handicapping conditions - such topics as nutrition, sexually transmitted disease, substance abuse, and communicable disease.

In Alaska, there is no State mandate for local schools to provide health curricula. The types of health education offered to Alaskan school children vary widely from district to district.

Public Awareness on Handicapping Conditions

Public awareness activities use a variety of media to inform the general public about handicaps. The purpose is to raise the consciousness of the general public. Activities can focus on preventing handicapping conditions, increasing awareness of the rights and the needs of persons with handicaps, and encouraging acceptance of community responsibility for these people.

In Alaska, a variety of groups and individuals undertake public awareness activities on the causes of handicapping conditions. Efforts can be local in nature, such as a component of a local health fair or a part of a school health curriculum, or regional/statewide, such as printing and dissemination of brochures or broadcast of public awareness spots.

Well-Child Programs

Well-child programs are prevention-focussed activities provided by physicians and nurses to screen children for normal physical growth and development. Included in these screening activities are a general physical assessment of the child; measurement of the child's developmental progress against established standards for child development; anticipatory guidance to parents on actions they can take to foster their child's development; and, referral to other sources when there is indication of a need for more extensive evaluation of possible handicapping conditions. The primary focus for these services is children aged 0-3, but the services may also be provided to children aged 3-5 or even older, depending on the needs of the child. In Alaska, well-child programs are commonly called "well-child clinics" or "early and periodic screening programs." In the villages and subregional centers, these services are provided by public health nurses on an itinerant basis. In the regional and urban centers, services are commonly provided by public health nurses at local health clinics or by private physicians and physician assistants.

Immunizations

Immunizations are vaccinations to prevent the occurrence of certain communicable diseases. Under Alaska law, each child entering school or licensed day care must be fully immunized for mumps, rubella, red measles, tetanus, diptheria, polio, and pertussis. Initial vaccinations are generally given to children between ages two and eighteen months, with appropriate booster vaccinations to children and adults as indicated.

In the villages and subregional centers, itinerant public health nurses administer immunizations in local health clinics. In regional and urban centers, vaccinations are administered by public health nurses at local health clinics and by private practitioners.

Early Identification Services

Prenatal Testing

Prenatal testing includes screening, diagnosis, and counseling services to pregnant women for the purposes of diagnosing medical conditions which may affect normal fetal development. This prenatal testing can include genetic testing (amniocentesis) for certain genetic defects (such as neural tube defects, Down's Syndrome, Tay-Sach's disease, and sickle cell disease). Prenatal testing may also include laboratory tests which indicate certain medical conditions of the pregnant woman. Prenatal testing is indicated for certain classes of "high-risk" pregnant women, including women over the age of 35, diabetics, those with elevated blood pressure, those who have borne a handicapped child or have a family history of certain types of handicaps, and those who have had a history of miscarriages.

In Alaska, the actual prenatal testing is offered only in urban centers and a few regional centers. If a woman from the rural part of the state is viewed as "high risk" by her regular provider of prenatal care, she is referred to a regional or urban center for appropriate testing.

Medical/Developmental Screening

Medical/developmental screening is the provision of a thorough physical examination, appropriate laboratory testing, and developmental testing by a pediatrician or other specialist to determine the exact nature of a suspected medical condition which may lead to a handicap. This service is the second level of screening of children who are already suspected as being at risk for a handicapping condition as determined through parental observation, well-child screening, or other sources.

In Alaska, this service is most commonly available in the regional and urban centers of the state where there are pediatricians in practice. If a child from an area of the state where there is not a specialist is suspected of having a handicapping condition, the child is taken to the location of the physicians. Native children tend to go to the Alaska Native Medical Center in Anchorage for this type of screening. Non-Native children go to private practitioners or (in the case of military dependents) to the nearest military medical facility where qualified professionals are available.

Vision and Hearing Screening

Vision and hearing screening is the periodic examination of school age children to detect hearing impairments and visual abnormalities. Its purpose is to identify those children who need treatment or corrective intervention.

Vision and hearing screening was mandated as a local school district responsibility by the 1982 Alaska Legislature. The standards for performance and training of local personnel for vision and hearing screening are to be developed by the Department of Health and Social Services. The services can be performed by professionals or trained lay persons, depending on the resources of the local school districts.

HEALTH SERVICES

	Recommended Service Per Level of Community			
Service	I	II	III	IV
Prenatal Care	L	L	L	L
School Health Curriculum	L	L	L	L
Public Awareness Activities			L	L
Well-Child Programs	I	L	L	L
Immunizations	I	L	L	L
Prenatal Testing				L
Medical/Developmental Screening	L	L	L	L
Metabolic Screening			L	L
Genetic Counselling			I	I
Diagnosis and Evaluation of Handicapping Conditions		L	L	L
Medical Services	I	I	L	L
Dental Services	I	I	L	L
Occupational Therapy	I	I	L	L
Physical Therapy	I	I	L	L
Speech and Hearing Services	I	L	L	L
Home Health Aide Services	L	L	L	L
Home Health Nursing			L	L
Genetic Counseling			I	I

L = Locally Available   I = Itinerant Service

Source: Governor's Council for the Handicapped and Gifted, 1983.

Metabolic Screening

Metabolic screening is the testing of newborns to identify metabolic disorders which may cause substantial handicaps. In Alaska, A.S. 18.15.200 (enacted in 1967) mandates that all newborns be tested for the following metabolic disorders: phenylketonuria (PKU), hypothyrodism, histidinemia, tyrosinemia, Maple Syrup Urine Disease, and congenital adrenal hyperplasia. All children born in hospitals are given the above-mentioned metabolic screening tests.

PKU and hypothyrodism are the two disorders which are most likely to result in substantial handicaps if undetected and untreated. The reported incidence of PKU in Alaska is approximately one case every three years. The incidence of hypothyroidism is approximately two cases every year. The Department of Health and Social Services, Section of Family Health indicates that, in the past eight (8) years, all cases of detected PKU and hypothyrodism have been treated successfully, thus avoiding substantial handicapping conditions for these children.

Diagnosis and Evaluation of Handicapping Conditions

Diagnosis and evaluation of handicapping conditions is the process of diagnoses, evaluating, and offering treatment to a person who is substantially handicapped. This service is the most rigorous of the early identification services. It requires a group of specialists to conduct required testing and offer interdisciplinary suggestions to the substantially handicapped person and/or the family on what can be done to ameliorate the effect of the diagnosed handicapping condition.

In Alaska, diagnosis and evaluation services may be obtained from private physicians and public medical services sources. The Department of Health and Social Services, Child Development Services is the State agency which provides itinerant diagnosis and evaluation services to a number of Alaskan communities. In the past couple of years, several regional/local interdisciplinary teams, including those in Bethel and Fairbanks, have been formed to provide a more localized service. People from southeast Alaska may travel to Seattle for diagnosis and evaluation.

Treatment and Rehabilitation Services

Medical Services

Medical services include basic and specialized care by a physician or allied health professional working under standing orders from a physician. In Alaska, medical services are provided in a variety of ways, depending on the area of the state, the ethnic background of the population, and the presence of military facilities.

In the villages and subregional centers, basic medical services are most frequently provided by community health aides, public health nurses, and physician's assistants. Native people usually travel to the nearest U.S. Public Health Service Hospital if there is a need for routine hospitalization services.

If a more complicated condition is indicated, Native people travel to the Alaska Area Native Medical Center in Anchorage for hospitalization. Non-Native people obtain primary care from community health aides, public health nurses, and physician's assistants. If hospitalization is required, they may receive primary treatment at the nearest U.S. Public Health Service hospital, or they may travel to a community or private hospital. People with more serious medical conditions requiring hospitalization tend to travel to Anchorage or Fairbanks for care and sometimes even to Seattle or other cities outside Alaska.

In regional and urban centers, there are again diverse patterns of care, depending on whether one is military, Native, or non-Native. Military personnel and their dependents usually receive routine medical care from the nearest military outpatient facility; hospitalization is generally in a military hospital. In some cases, a military person or dependent can receive care at a non-military facility. Native people living in regional centers and urban centers usually receive primary outpatient services at the local Alaska Area Native Health Service clinic. If hospitalization is required, Native people are generally sent to the Alaska Native Medical Center-Anchorage. In some cases, AANHS will arrange to contract services with a local community or private hospital. In the past couple of years, however, this practice has declined due to changing policies of the U.S. Public Health Service and budget cuts. Non-Native, non-military people tend to look for outpatient services at either private clinics or local State-funded health centers; hospitalization is generally at the local hospital.

In cases where a person, regardless of military status or ethnic background, has a medical condition which requires extremely complicated or delicate medical intervention, that person will sometimes seek treatment in an out-of-state medical facility. Seeking treatment in an out-of-state facility has been a fairly common practice for people with substantial handicaps, but this practice appears to be on the decline.

The Department of Health and Social Services' Handicapped Children's Program is a major third-party payer. This program provides funding so families with handicapped children can seek expensive, specialized medical care.

Dental Services

Dental services relate to the health and care of the teeth and gums. Dental services for people with substantial handicaps are extremely important because of the fact that certain handicapping conditions and medications given to handicapped people may create oral problems.

In Alaskan villages, most dental services are itinerant. The dentists who provide these services are employees of the U.S. Public Health Service. The frequency of visits to villages varies from one every two years to several times a year.

In subregional centers, dental services are provided by a variety of methods. Some subregional centers have resident dentists; other receive dental services on an itinerant basis. Depending on the ethnic composition of the population, dentists may be in private practice, employees of AANHS, or military affiliated.

In regional and urban centers, people have local access to dentists and, in some cases, to orthodontic specialists and dental surgeons.

Fluoridation of drinking water supplies is not typical in most villages and subregional centers in Alaska. In contrast, most regional centers and both urban centers have fluoridated water supplies.

In general, the rural areas of the state are considered manpower shortage areas in terms of adequacy of dental services. The State Health Plan cites these areas.

Occupational Therapy

Occupational therapy is the application of purposeful, goal-oriented activity in the evaluation, diagnosis, and/or treatment of persons whose function is impaired by physical illness or injury, emotional disorder, or congenital or developmental disability. The goal is to achieve optimum functioning, to prevent disability, and to maintain health. Occupational therapists plan activities that help disabled persons develop self-help skills and adapt the house and equipment to be most conducive to independent living.

There are no locally-available occupational therapy services in the villages and itinerant services are rare. Even in subregional centers, there are generally no resident occupational therapists. School districts may contract with a private consultant to provide services on an as-needed basis. In both villages and subregional centers, ongoing exercises prescribed by a registered occupational therapist are generally left to the family or community members to implement.

Occupational therapy services are available in some regional centers. Occupational therapy services are frequently available in nursing homes, hospitals, and schools. In-home receipt of services are much more uncommon. Some communities have worked out agreements among agencies to share professional occupational therapy services.

Physical Therapy

Physical therapy helps a disabled person to develop his or her physical abilities and to use muscles by use of heat, light, water, electricity, massage, and therapeutic exercise. Professional services are rendered by registered physical therapists who may either prescribe a regimen of therapy to be conducted by a trained lay person or may provide the service directly. In Alaska, the availability of physical therapy services follows about the same patterns as does the availability of occupational therapy services. The Elks Society support and employed physical and occupational therapists who provided itinerant services, particularly to Southeastern communities, and locally in Level III communities, before these services became available through schools and hospitals.

Speech and Hearing Services

Speech and hearing services include identification, diagnosis, and treatment of defects in speech and hearing. Generally, speech and hearing services are comprised of two separate but interrelated disciplines audiological services and speech pathology. Audiological service is the evaluation of hearing defects and the treatment or rehabilitation of those who have hearing loss. Speech pathology is the evaluation of speech defects and the treatment of rehabilitation of those who have speech defects.

In Alaska, audiological services are generally provided on an itinerant basis. The Department of Health and Social Services' Communicative Disorders Program is the primary audiological service provider. This service is organized to provide resident audiologists in Fairbanks, Anchorage, Sitka, Bethel, and Nome. Each of these regional audiologists provide itinerant coverage to the rural areas surrounding their respective regional office. Audiologists test hearing function, prescribe hearing aides and other assistive devices, and refer people with need for further medical treatment or rehabilitation to the appropriate medical specialist or program.

Speech pathology services in Alaska are provided by the Department of Health and Social Services' Communicative Disorders Program, school districts, and a limited number of private treatment organizations. The speech pathologist employed by the Communicative Disorders Program is stationed in Anchorage and commits approximately 50% of her time to itinerant diagnostic work. The remainder of this professionals' time is spent in consulting with Child Development Services for purposes of providing speech pathology input to multidisciplinary diagnostic evaluations of children with handicaps and/in consulting with local school districts for purposes of designing prescriptive speech therapy programs to be conducted by school speech therapists. Approximately one-half of the local school districts employ or contract for speech pathology/speech therapy services. These school-provided services are generally more available in the regional and urban centers than they are in the villages and subregional centers. Alaska Crippled Children and Adults provides speech pathology services to people in the Fairbanks and Anchorage areas. The Alaska Treatment Center, a private agency located in Anchorage, provides contract speech pathology services to some schools and to other agencies in the state.

Home Health Aide Services

Home Health Aide services are a major service which can delay, prevent, or cut short hospitalization, nursing home or out-of-home placement of people with substantial handicaps. Aides (under supervision of registered nurses) help with the physical care of a handicapped person on a regular daily or weekly basis. They can change dressings, assist with feeding, positioning, bathing, grooming, health care, and use of adaptive devices. Home Health Aides are employed by the Division of Public Health and provide services in Juneau, Anchorage and Fairbanks. This new service is not yet funded or available in Level I, II, or most Level III communities.

Home Health Nursing

Home Health Nurses can provide full range nursing services which are usually provided in hospital or nursing homes in a disabled person's own private residence. For people with more complex medical and health care needs, home health nurses are needed to prevent placements in health care facilities. Disabled people recovering from surgery, illness, or who require skilled nursing may receive such care from registered nurses under the Medicare program if eligibility requirements are met and the services are prescribed by a physician. Services are part-time. Before Medicare funding for home health care services became available home health nursing was only available privately through private payment or insurance. Presently the Division of Public Health funds these services to a limited extent in Juneau, Fairbanks, and Anchorage.

Support Services

Support services are those services which are needed in addition to adequate medical care, usually before and in conjunction with educational and vocational services. These services are also called "Home and Family Support Services". They are difficult to define because their primary characteristic is their ability to respond to individual needs. The people interviewed in the Council-sponsored Doyon Project identified three related purposes for home and family support.

1. To help people remain in or return to their own homes rather than having to live in congregate living arrangements.
2. To support people's participation in family, neighborhood, and community life.
3. To assist people to develop or restore their abilities.

Home and family support services can focus directly on the person with a disability or on another household member, or on the household as a whole.

One Alaskan mother from Fairbanks said these services:

> (Support services)"...fill up the spaces between what my daughter's day program can do for her and what our family can do for her. By itself, it's not any one big thing. It's several little things. But our family life and our daughter's life are much better because of it."

What each family or individual will need to "fill up the spaces" will vary and change over time. It doesn't necessarily make sense to assume that individuals and families will need varying amounts of the same support services in the same way that they might need varying weekly amounts of whole milk. It makes more sense to ask, "What kind of assistance does your family need right now?" (O'Brien and Lyle, Focus Document for a SEARCH Conference, 1982)

A man from Galena, a subregional center located on the Yukon River in the central region, defined a second important characteristic of these support services, using the specific service known as "homemaker service" as an example:

> "It was more for my family than for me. I could look after myself, and my brother made sure that we had wood and water. I did some of the cleaning but I couldn't do all the cooking and cleaning for myself and my four kids. I need help with that.
>
> "It was good that (the homemaker) came and did what I needed and not more. And it was good that when I didn't need them anymore they stopped coming."

Home and family support services will be effective if the people and families who use them experience them as being:

FLEXIBLE	- if service workers respond to different personal and family needs as active problem solvers. As a result, support activities change as personal, family, or other service circumstances change.
EMPOWERING	- if service workers find out what a person with a disability can do for him/herself, and what others in the household, neighborhood, or extended family can do with and for the person with a disability. Home and family support activities BUILD ON WHAT'S ALREADY AVAILABLE to a person. They extend and expand what natural support systems can do.
COMPETENT	- if service workers have the knowledge and skills to help people and their families develop realistically high expectations of themselves and services and then work systematically to meet them.
ACCEPTABLE	- if service workers are sensitive to service users cultural values and preferences. Many home and family support activities are personal; some are intimate. Making and keeping a positive relationship often means taking extra effort to accommodate people.

These four elements are closely related. Together they create a personalized service. (O'Brien and Lyle, The Future of Home and Family Support Services in Alaska's Doyon Region: A Focus Document, 1982)

Support services are the "front line" in building on already existing informal resources and providing formal assistance to people with handicaps and their families. In an attempt to provide some structure to the term "support services", definitions of specific services which add considered support services when they are used to assist people to live independently or with their families are listed below.

Maintenance Services

Maintenance services support or augment the family's efforts to properly care for a handicapped member living with them. In the case of a disabled adult living with a spouse or living independently in the community, maintenance services support or augment the individual's efforts at self-care and care of the home.

Day Care/Sitter/Specialized Sitter (Respite) Services

Supportive maintenance services provide basic care, supervision, and guidance to the substantially handicapped person when the regular caregiver(s) cannot provide the needed supervision.

Day care is the care, supervision, and guidance of a handicapped child on a regular basis. Care is provided by someone outside the child's immediate family in day care centers, family day care homes, or the child's home at any time of any day or night for periods of less than 24 hours. Parents usually use day care so that they can work or go to school.

Specialized sitter services provide occasional, short-term, temporary care of a child or adult and are designed for persons with handicaps. The training of the temporary caregiver is generally more specialized than that of a typical "sitter".

Day care services are sometimes provided informally such as when neighbors help each other with child care. In more formal situations, care may be provided in an unlicensed or licensed day care home or in a licensed day care center. Licensed day care homes and centers are common in regional and urban centers and are just beginning to be developed in the subregional centers and villages. There is one specialized day care facility in Anchorage which is designed to meet the special needs of children with substantial handicaps.

Sitter and specialized sitter services are also provided both formally and informally. For families with non-handicapped children, it is common practice to enlist the help of a teenager or adult neighbor or friend when the parents/caregivers wish to pursue other activities for a short period of time. For families with a substantially handicapped family member, it is not always as easy to get this type of assistance. In seven communities - Anchorage, Fairbanks, Kenai, Juneau, Ketchikan, Sitka, and Kodiak - the State has funded specialized sitter programs, commonly known as "respite care." The characteristics of these programs vary widely and are discussed in the respective regional chapters of this plan.

Homemaker Services

Homemaker service is the assistance of a paid paraprofessional who provides part-time help in keeping a household functioning in cases where people cannot conduct routine household chores and management for themselves. The primary responsibility of a homemaker is assistance with housekeeping tasks such as routine cleaning, chopping and hauling wood and water, personal laundry and mending of clothes, meal planning and cooking, and shopping and simple errands. If a need is indicated, a homemaker can also provide a limited amount of personal assistance in such areas as grooming, dressing, bathing, and assisting a person in moving about his/her home.

Homemaker services in Alaska are available in a limited number of villages and subregional centers and are generally available in regional and urban centers. They are funded by the State and administered by contracts to two different organizations. Alaska Management Technology, Inc., is the primary contractor providing services. The Maniilaq Association has an individual contract to provide homemaker services in the Kotzebue Sound subregion of the northwest region. To get assistance from a homemaker, a person contacts the local office of the Division of Family and Youth Services which screens the application and refers the person for service when appropriate.

Personal Aides and Attendants

Personal aides and attendants provide personal care and housekeeping/chore services to substantially handicapped persons on an on-going, regular (sometimes live-in) basis. Personal aides and attendants are generally appropriate for people who are very substantially handicapped. The personal aide or attendant meets the basic survival needs of the substantially handicapped person, thus freeing the individual to participate in an educational or vocational program or to enter or maintain employment.

In Alaska, personal aides and attendants are generally not available. One notable exception is in the Municipality of Anchorage, where a non-profit agency began offering this service to substantially physically handicapped young people in 1982.

Transportation

Transportation services enable substantially handicapped individuals who cannot travel by personal auto or public transit unassisted to travel to and from essential community services, including work, shopping, health services, recreation, and other services. In areas of the state where travel by personal automobile or public transit is not typical for the general population and where people fly to distant communities for certain services (especially health services), transportation can mean air travel.

Recreation

Recreational opportunities for people with substantial handicaps vary widely, depending on the part of the state and the type of handicap of the person. Many people with substantial handicaps can participate in recreational opportunities available for the general public such as camping, swimming, and certain types of organized sports. At times, certain accommodations and assistance must be available to help people access these opportunities. For example, a teenager with cerebral palsy might very well be able to go with his friends to use the local swimming pool if there is a way for him to enter and exit the pool and dressing rooms. For some people, access to recreational opportunities is more limited because of the lack of accessible facilities or needed supervision and organization of activities.

In Alaska, recreation takes different forms for almost everybody. For some people, recreation is a walk in the woods or casting a line in a local stream. For other people, recreation means mountain-climbing, deep-sea fishing, or sailing. For still other people, recreation can mean the use of community facilities for organized sports participation such as playing softball, swimming, or cross-country skiing. There are several non-profit groups which organize recreational opportunities for people with substantial handicaps. Most of the organized activities are available only in the urban and regional centers. An example is the Special Olympics, which sponsors organized competitive track and field events for the exclusive participation of children and young people with handicaps. A non-profit group was recently started in Anchorage to organize outdoor recreational activities such as skiing and mountaineering for physically disabled people.

Developmental Services

Developmental support services are formally-organized activities which foster the substantially handicapped person's skills for independent living and assimilation into the community. These services focus on developing the capabilities of the substantially handicapped person and augmenting the capability of the family unit in assisting their handicapped family member in reaching full potential.

Family training is the provision of information and emotional support to the family of a substantially handicapped person in dealing with life crises, fostering the development of their handicapped family member, and working out positive group dynamics for the family unit. Some of the more informal ways of providing this service include seeking advice from a person who has been through a similar situation or soliciting the advice of a professional who may provide other services (such as a nurse or teacher) on how to handle a particular family situation. More formal approaches include seeking the assistance of a professional who is trained in dealing with family interactions involving people with substantial handicaps.

Counselling services imply a more intensive type of service focused on the resolution of problems in living. Counseling may be offered to the family and/or to the individual who is handicapped.

In Alaska, there are a variety of formal services available for individuals and families. Community mental health centers, funded by the State, offer services to individuals and families in coping with life crises. Some of the mental health centers offer group activities specifically for persons with handicaps which are focused on increasing coping skills. In some of the regional centers and in both urban centers, there are non-profit agencies which specifically focus their services on training people in good parenting skills. In Fairbanks, a pilot service has been initiated to assist parents in understanding the school-day regimen for their child and developing appropriate interventions at home which are compatible with those used in school.

SUPPORT SERVICES

Service	Recommended Service Per Level of Community I	II	III	IV
MAINTENANCE SERVICES				
Day Care Home/Sitter/Specialized Sitter (Respite Care)	L	L	L	L
Day Care Center			L	L
Homemaker	L	L	L	L
Personal Aides and Attendants			L	L
Transportation	L	L	L	L
Recreation	L	L	L	L
DEVELOPMENTAL SERVICES				
Family Counseling and Training	I	L	L	L
Individual Counseling	I	L	L	L
Personal and Social Skills Development	L	L	L	L
Independent Living Skills Training	L	L	L	L
MATERIAL SUPPORT SERVICES				
Financial Assistance	L	L	L	L
Environmental Adaptive Equipment	L	L	L	L

L = Locally Available I = Itinerant Services

Source: Governor's Council for the Handicapped and Gifted, 1983.

Personal and Social Skills Development

Personal and social skills development is training provided either independently or as part of another service (such as homemaker service) to a substantially handicapped individual to assist him or her in developing behaviors and skills appropriate to self-care, communication, mobility, self-direction, and social interaction. The acquisition of appropriate personal and social skills is seen as a prerequisite to independent living skills training. Personal and social skills training could include acquisition of eating and drinking skills, toileting skills, personal hygiene skills, interpersonal skills (such as sharing, courtesy, cooperation, and responsibility), and grooming skills. This type of service can be provided by a variety of professionals and paraprofessionals including homemakers, educators, home health nurses and aides in addition to or to provide training to parents who have primary responsibility for fostering the development of their children.

This service is generally provided as part of other services that a substantially handicapped person may be receiving. Schools may assist children in acquiring proper toileting skills. A home health nurse or physical therapist may show a person how to use a prosthetic device or care for his/her body. Parents probably spend more time in providing this service than anybody else. In Alaska, there are no special programs called "Personal and Social Skills Development Programs" but there are many services which include this as a component of their program. Few families have direct access to this service except as a part of another service.

Independent Living Skills Training

Independent living skills training assists substantially handicapped persons to acquire the daily living and community survival skills that enable them to make decisions affecting their lives, to carry out activities that a non-disabled person would take for granted, and to pursue training and employment. Skills which might be acquired through this type of service are: social skills; using personal adaptive equipment such as wheelchairs and prosthetic devices; management of personal aides and attendants; budgeting and fiscal management skills; household management skills such as cooking, shopping, housework, and maintenance of clothing; time management skills; development of leisure time skills and activities; and pre-vocational skills such as appropriate dress and work behavior.

Schools provide many independent living skills training activities through special education programs. State-funded independent living skills training programs for adults are available in the Bethel area, Anchorage, Fairbanks, Juneau, and Ketchikan.

Material Support Services

Financial Assistance, Environmental Adaptive Equipment, Personal Adaptive Equipment

Material support services provide or assist substantially handicapped individuals to obtain and maintain equipment, aides, and devices that are necessary for daily living or to meet special needs. These services include financial assistance, such as Public Assistance or family subsidies, environmental adaptive equipment and personal adaptive equipment. Personal adaptive equipment includes prosthetic limbs and mechanical devices which are needed to ameliorate functional limitations in self-care, learning, and mobility. Environmental adaptive equipment includes personal computers for people who are physically handicapped, retrofitting of kitchens and baths, ramping of a dwelling, making accessible public buildings and restrooms, and installing handbrakes and hand accelerators or foot steering in personal vehicles.

Acquisition of personal adaptive equipment appears to be more easily accomplished than is the acquisition or installation of environmental adaptive equipment. The Division of Vocational Rehabilitation sometime assists in purchasing personal equipment for adults or retrofitting or adapting housing. Alaska does not yet have a family subsidy program to assist families with purchasing costly equipment or services. Fifteen other states have such a program and the U.S. Department of Human Services is investigating this service alternative. The Department of Health and Social Services' Handicapped Children's Program provides assistance to children who need personal adaptive equipment.

Under federal law (the Rehabilitation Act), all public facilities constructed after 1973 are supposed to meet the barrier-free requirements cited in the Architectural Barriers Act. In Alaska, some public buildings meet these requirements, while others do not. Additionally, the meaning of "barrier-free" takes on a different meaning in Alaska than it does in part of the country where temperatures are not so extreme. It is very possible to have a barrier-free building to which a handicapped person would not have access to because he/she could not get to the building.

Residential Options - Places to Live

The environments in which people live can be characterized by the extent to which they fit typical community housing situations and by the amount of personal freedom and individual control over daily activities a handicapped person and his or her family has. These contexts and residential settings are categorized as natural, augmented, and protective. Natural and augmented environments tend to be less restrictive, more individualized settings than devised environments. Protective settings are most restrictive of personal choice and freedom because of large physical size and number of people living together.

Natural environments

Natural environments are simply the personal homes or apartments in which most of us live. We choose them according to our own personal criteria such as proximity to schools, shopping, in-town or out-of-town location, driving distance to work, access to public transportation, and, of course, affordable cost. Such natural or typical residences or apartments should be the primary focus of residential services for people with substantial handicaps. This is in keeping with A.S. 47.80. In fact 95% of people with handicaps do live in typical community housing which they purchase, rent, or lease, and for which they are financially responsible.

Family, Foster Home, Adoptive Home

For children, natural residential options include living with one's own family either through birth or adoption, and foster care. For adults, these include owning or renting one's own dwelling either independently, or with spouse or friends, or, in some cases, living with one's own family. A residential option for people with substantial handicaps is considered to be in the natural environment if there are no special support services made available to the person or family other than those used by or available to people who are not handicapped.

Augmented environments

Augmented environments are created when services such as homemaker, personal aide and attendant care, subsidized adoption, co-operative apartments rented by an agency, independent living skills training or specialized support services are provided in typical housing and natural settings to enable people to live as normally as possible.

Most people with handicaps strive to maintain or achieve personal self-sufficiency and independence. Therefore services which support personal control, personal decision-making, and provide people with skills and resources which help them live at home in their community are most desirable and appropriate.

Infant learning, respite care, day care, personal aides, homemaker and home health services, all described separately in the plan, are augmented services which support people in their own homes. In addition there are ten specialized programs offered by five agencies in Anchorage and Fairbanks which provide residential support services to children and adults.

Subsidized Adoption

Subsidized adoption is a possibility for special needs children who could not ordinarily be adopted because their costs of care are so high. The Division of Family and Youth Services subsidizes adoptions of nine children presently.

Specialized Foster Care

For children who cannot remain with their natural families because of abuse, neglect, inability or unwillingness to care for their children, it is still possible for the children to live in a natural/augmented environment. Foster care and specialized foster care do not sever legal relationships with natural family. Foster families, licensed by the Division of Family and Youth Services, can accept no more than five children, two of whom may be substantially handicapped. Foster home placement may be either short-term until the natural family can resolve the problems which threatens the well-being of the child, or long-term, in cases where return to the natural family is not anticipated. For some substantially handicapped people, foster care has been provided, not because of natural family unwillingness or inability to care for them, but because the out-of-home residential care was part of a service "package" where, in order for a child to receive necessary medical, educational, and developmental services, it was necessary for the child to move away from home to a Level III, IV, or V Community. Recently, an adult foster care program has been started by the Division of Family and Youth Services for disabled or elderly adults.

Semi-Independent Living Programs

Semi-independent living programs for adults are also called apartment programs, independent living programs, or transitional apartments, co-resident apartments, or cooperative apartments. Depending on the individual needs of the substantially handicapped adult, the character of a formally-organized or agency supported apartment program will vary. People who are mentally alert but severely physically disabled may need personal aides and attendants, specially designed transportation and material support services to enable them to live in the community. People with mental retardation may need on-going independent living skills training and scheduled visits from someone who checks their general well-being, helps with money management, and provides opportunities for social and recreational activities.

Available in Fairbanks, Anchorage, Juneau, and Ketchikan, these programs are characterized by having the majority of decision-making and responsibility for daily living activities left in the hands of the substantially handicapped person. They are called "programs" when it is the responsibility of an individual agency to provide or arrange for provision of the individually required and planned support services.

An additional semi-independent living program for substantially handicapped adults is a situation where two or more people pool their resources and buy a dwelling. Necessary support services are provided to these people. This type of residential option, not currently utilized in Alaska, is called cooperative housing.

Devised Environments

Devised environments are group residences which are specially adapted and staffed to provide care to a particular population and age group. They are generally dispersed in residential neighborhoods, provide residential care for ten or less (preferably five or less) unrelated individuals. Devised environments for handicapped people include group homes for the developmentally disabled, adult residential care facilities, and child caring facilities all operated by private-non-profit groups under contract with the Division of Mental Health and Developmental Disabilities, or the Division of Family and Youth Services.

Of the 123 people served in F83, 81 are in Anchorage, 18 in Fairbanks, 9 in Bethel, 6 in Juneau, 6 in Ketchikan, and three elsewhere.

If a facility houses more than ten people and exerts almost total control over the daily activities of the residents, it is considered to be a protective environment.

Group Homes

Group homes are small community residences which house ten or fewer substantially handicapped children or adults plus house parents and/or residential counselors. The ratio of staff to residents will depend on the severity of the residents' functional limitations. Group homes are sometimes called "small group homes" (4 beds or less) or "large group homes" (5-10 beds). People who live in group homes are dependent on the community for support services.

In Alaska, group homes are primarily utilized by people with mental retardation or by children who have been placed out of their family home because of family problems and/or behavior problems. All group homes of four beds or more must be licensed by the State. Currently, the only group homes for children are located in Anchorage and Juneau: group homes for adults are located in Anchorage, Fairbanks, Juneau, and Ketchikan.

Boarding Homes

Boarding homes are residential options for dependent adults; they provide basic board and room services. Boarding homes generally serve a fairly large number of adults who are capable of managing their daytime activities basically unsupervised. Boarding homes are considered residential options in the devised environment because of the fact that they generally provide service to more than ten people. At present, boarding homes are available only in Anchorage and Bethel. Residents of these facilities are highly dependent on the community for provision of needed support services and appropriate daytime activities such as employment or training.

RESIDENTIAL OPTIONS

Service	Recommended Service Per Level of Community I	II	III	IV
OPTIONS IN THE NATURAL/ AUGMENTED ENVIRONMENT				
Family or Own Home	L	L	L	L
Foster Care	L	L	L	L
Adoption	L	L	L	L
Subsidized Adoption	L	L	L	L
Specialized Foster Care	L	L	L	L
Semi-Independent Living Environments for Adults	L	L	L	L
OPTIONS IN THE DEVISED ENVIRONMENT				
Group Homes		L	L	L
Boarding Homes			L	L
Safe Houses	L	L	L	L
Receiving Homes			L	L
Women's Shelters			L	L
Emergency Housing			L	L
OPTIONS IN THE PROTECTIVE ENVIRONMENT				
Residential Treatment Centers			L	L
Nursing Homes			L	L
Correctional Facilities				L

L = Locally Available

Source: Governor's Council for the Handicapped and Gifted, 1983.

Shelters

A third classification of residential options in the devised environment are termed shelters. Included in the category are safe houses, receiving homes, women's shelters, and emergency housing.

Safe houses are personal dwellings in villages and subregional centers which are known by community members as places where a person (usually a woman) can seek temporary lodging when her regular living situation poses a threat to her personal safety. Use of a safe house is a voluntary activity, as is the opportunity to leave the house when the crisis period has passed. Generally, the person who owns and lives in the safe house on a regular basis is a trusted member of the community who may be looked to for emotional support and counseling on how to cope with the crisis situation.

Receiving homes are temporary residential options for children and teenagers who are at risk of abuse or neglect. These facilities are generally operated by paid staff who have custodial responsibility for the children living in the facility. Admittance to these receiving homes is through referral by the local Division of Family and Youth Services social worker. Receiving homes provide care for only a short period of time for some children. Other children's normal living situations are such that they return again and again to the local receiving home for short stays.

Women's shelters are a more formal version of safe houses in that they provide temporary haven to women and their children when the normal living situation for these people has deteriorated to the point that the women and children are at risk of or are being abused. Women's shelters have developed in response to needs for protection of dependents in cases of domestic violence. The staff of these women's shelters offer counseling and emotional support to the residents in crisis resolution.

Emergency housing is provision of temporary shelter to people who are indigent. Services include basic room and board. Emergency housing is typically operated by charitable organizations in response to situations where people find themselves "with no place to go." In some cases, the staff of these emergency shelters offer counseling to the residents and attempt to find these people employment or suitable long-term housing.

Protective Environments

Residential placements in the protective environment are the most restrictive of all residential options. They are generally self-contained facilities which serve more than ten people. These facilities rely very little on the community to provide needed support services to residents, since these services are provided by the facility itself. These residential options may be appropriate for people who are medically fragile or who pose a threat to themselves or others. Protective residential options allow very little opportunity for individual residents' decision-making about their daily affairs; the size and structure of these facilities dictates the need for routine schedules for providing meals, personal hygiene, and sleeping times. People who live in protective residential settings may make this choice voluntarily. However, they can be "committed" to some protective facilities by court order placed by state agency workers if they are in state custody, or family members can decide to place them in this type of residential environment.

Residential Treatment Centers

Residential treatment centers are facilities of ten or more beds which provide a protective setting for children in need of temporary separation from their families. These children often have emotional problems or behavior disorders. Frequently they have had minor skirmishes with the law but have probably not been adjudicated delinquent by court order. The primary purpose of these treatment centers is to offer a protective setting for a relatively short period of time (usually less than a year) and to provide appropriate treatment services to help the child overcome his/her problems.

Nursing Homes

Nursing homes are self-contained facilities which provide residential and medical care on a long-term basis to people with severe medical problems. There are two basic types of nursing homes: skilled nursing facilities (SNFs) and intermediate care facilities (ICFs). The basic difference between these two types of nursing homes is that SNFs are licensed to provide more intensive care than are ICFs. Nursing homes provide special medical attention, stimulation of abilities, and comprehensive recreation opportunities based on the general needs of the residents.

Institutions

Institutions are self-contained facilities of ten beds or more which provide structured and closely supervised residential care for people with substantial handicaps. The major type of institution which provides care to people with substantial handicaps is called an Intermediate Care Facility for the Mentally Retarded (ICF-MR). Other types of institutions include large psychiatric hospitals. Institutions often offer medical-model programs utilizing staff who are primarily health care professionals. Services such as medical care, recreation, education, training, and so forth are brought into these facilities rather than the individuals going into the community to receive them. These types of programs are self-sufficient to the point that the community in which they are located may be dependent on the facility for employment.

Correctional Facilities

A final classification of protective residential options is correctional facilities. Correctional facilities are self-contained, usually locked facilities into which people are placed by court order because of crimes committed. Correctional facilities can be designed for either children or adults and vary according to the amount of freedom given to the inmates. Correctional facilities for juveniles can include residential treatment centers when it is in the best interest of the child who has been adjudicated delinquent that he/she be placed in a more relaxed (though still protective) setting. The type of daytime programming offered in correctional facilities also varies, depending of the treatment philosophy of the particular facility.

Educational Services

Educational services develop the knowledge levels and skills of people so that they can be full, contributing members of society within the limits of their abilities. These services help people with substantial handicaps to reach their full potentials. Educational services include activities from birth onward and are divided into four subgroupings: 1) infant learning programs; 2) pre-school programs; 3) special education services; 4) and post-secondary and adult education services.

Infant Learning Programs

Under A.S. 47.20, the Department of Health and Social Services administers "infant learning programs." The intent of A.S. 47.20 is "to provide appropriate public education and training for exceptional children in this state who have not reached the age of three. To the maximum extent possible, the department shall establish a learning program which emphasizes individual needs, is home based, and involves parents in the education and training of their children."

There are seventeen locally-based infant learning programs in Alaska. There are also two statewide itinerant programs to meet the special needs of visually-impaired and hearing-impaired children. These programs provide early identification, intervention, and training, using the family as the primary teacher and provider, to encourage the mental and physical development of infants and toddlers so as to reduce the long-term effects of handicapping conditions.

Coverage of infant learning program services to the villages and subregional centers is dependent on whether there is an infant learning program located in the nearest regional center which has itinerant responsibilities. Even if there is a regional infant learning program available, coverage may not be complete to all communities in the surrounding areas due to budget constraints. Where programs are available, the trained professional infant learning teacher usually makes monthly visits to the family, assesses the needs of the child, develops a program of instruction, and trains the parents (or other caregivers) on how to implement the program.

In regional and urban centers, services are available locally. The general pattern of service is for the infant learning teacher to visit the home on a weekly basis, provide assessment, develop a program of instruction, and train the parents on how to implement the needed instructional activities. The Fairbanks program has a center-based component which allows parents and children to come to a center for additional training.

Infant learning teachers also screen children who are suspected of having a developmental delay and arrange for other services which may be needed such as arranging for necessary therapy services and referral for needed medical services or material support devices.

It should be noted that, while A.S. 47.20 provides for assistance to groups wishing to provide infant learning services, it does not guarantee the right to a free and appropriate education for all children under the age of three. Until 1985, the State is required under P.L. 94-142 to provide a free and appropriate education to all exceptional children aged 3-19. In 1985, this law will be extended to all exceptional children aged 0-21. Activities are underway to make sure Alaskan infant learning services will meet P.L. 94-142 requirements by 1985.

Pre-School Programs

Pre-school programs provide educational opportunities for substantially handicapped children aged 3-4. The term includes Headstart programs, which are federal/State-funded programs designed to offer an early educational experience to disadvantaged children, and local district pre-school programs, which are mandated to be provided by P.L. 94-142.

Headstart Programs

Under federal law, 10% of all children enrolled in Headstart programs must be children with special needs. There are Headstart programs located in the southeast, south central, central, west, and northwest regions of Alaska. These programs are scattered among villages, subregional centers, regional centers, and urban centers. Handicapped children who are enrolled in Headstart programs have their special needs met in a variety of ways. A Headstart program may enlist the services of the local school district to evaluate children suspected of having handicaps and request that the school district provide special services, such as speech therapy, to these children as a part of their Headstart experience. In some communities, agreements between the local school district and Headstart programs have resulted in the school district meeting its responsibilities to provide special education services through the support it gives to children with special needs who are enrolled in the local Headstart program. In other communities, the school district provides additional special education services to these children.

Local District Pre-School Programs

As stated earlier, under P.L. 94-142, all exceptional children aged 3-19 must be provided with a free and appropriate public education. The provision of these services is the legal responsibility of the school district in which the child resides. The services provided will vary according to the individual needs of the child and are provided according to an Individual Education Plan (IEP) developed jointly by appropriate school district personnel, parents, and consultants (where appropriate).

EDUCATIONAL SERVICES

	Recommended Service Per Level of Community			
Service	I	II	III	IV
Infant Learning Programs	I	L	L	L
Pre-School Programs	L	L	L	L
Special Education Instruction				
Regular Classroom	L	L	L	L
Regular Classroom with Supplements	L	L	L	L
Regular Classroom with Resource Room	L	L	L	L
Self-contained class or resource room			L	L
Special Education Day School				L
Hospital, Treatment Center, Correctional Facility			L	L
Home-Bound or Correspondence Study	L	L	L	L
Related Education Services				
Transportation	L	L	L	L
Speech Pathology and Audiology	I	I	L	L
Psychological Services	I	I	L	L
Physical and Occupational Therapy	I	I	L	L
Recreation	L	L	L	L
Early Identification and Assessment	L	L	L	L
Diagnostic and Evaluative Medical Services	I	I	L	L
Counseling Services	L	L	L	L
School Health Services	L	L	L	L
Social Work Services			L	L
Parent Counseling and Training	L	L	L	L
Post-Secondary and Adult Education Services		L	L	L

L = Locally Available   I = Itinerant Service

Source: Governor's Council for the Handicapped and Gifted

Less than half of the 53 school districts in Alaska offer independent pre-school special education programs for exceptional children aged 3-4. Other school districts meet their responsibilities by supporting the special services needs of children enrolled in local Headstart programs.

Special Education and Related Services

The Education for All Handicapped Children Act, Public Law 94-142, was passed by Congress in November 1975. It includes provisions designed to:

1. Assure that all handicapped children have available to them a free appropriate public education.
2. Assure that the rights of handicapped children and their parents are protected.
3. Assist states and localities to provide for the education of handicapped children.
4. Assess and assure the effectiveness of efforts to educate such children.

All handicapped children in Alaska age three to nineteen are entitled to a free appropriate public education. Parents, guardians and professionals entrusted with legal custody of developmentally disabled children as well as classroom teachers need to know their child's rights to education and to follow the due process requirements of P.L. 94-142 and local school district policies for the following:

a. notification of need for special education services.

b. obtaining parental permission before testing.

c. parental approval of the child's individual education program and placement.

d. annual review of the education program.

e. right to ask for additional testing if parent or responsible adult disagrees with initial test results.

f. right to appeal placement of child in special education.

g. right to impartial hearings and appeal at the local and state education agency levels and ultimately to judicial review if parental agreement with diagnosis, educational plan and placement is not obtained.

The Education for All Handicapped Children Act requires states and local school districts to prepare detailed plans showing how they will meet the conditions of the law which include the following requirements:

1. The state will provide all handicapped children with "full educational opportunities" and a specified percent of the federal funds will be given to children who are receiving no education at all. A timetable must be established for the "full service" goal.

2. Policies and procedures will be instituted to safeguard due process rights of parents and children.

3. Handicapped children will be educated with non-handicapped children to the maximum extent possible for each individual child.

4. Tests and other materials or methods used to evaluate a child's special needs will be neither racially nor culturally discriminatory.

5. Information gathered concerning a handicapped child will be kept confidential. Parents must not be denied the opportunity to see relevant school records (O'Donnell, 1977).

The Education for All Handicapped Children Act and The Alaska Special Education regulations require that an individualized education program (IEP) be written for each child receiving special education. This program is to be developed at a meeting at which the following people are in attendance:

1. A representative of the local education agency who is qualified to provide or supervise the provision of special education.

2. The teacher of the child.

3. The parents or guardian of the child.

4. Whenever appropriate, the child.

The individualized education program (IEP) is to include 1) a statement of the child's present level of education performance; 2) a statement of annual goals; 3) a statement of the specific educational services to be provided; 4) the extent to which the child will be able to participate in regular education programs; 5) the date of initiation of the program and its anticipated duration; 6) the appropriate objective criteria, evaluation procedures, and schedules for doing at least an annual review to see whether instructional objectives are being achieved.

The IEP was mandated by the law so that a child with special needs can be reasonably assured that she/he is receiving an educational program suited to her/his needs. There are many safeguards included to insure that the program is developed by those who know most about the child's needs-parents, teachers, specialists in the area of the disability, and possibly the student.

Special classes, separate schooling, or other removal of handicapped children from regular classes may only occur when education in regular classes with the use of special aids and services cannot be achieved satisfactorily. P.L. 94-142 defines handicapped children as those who are: mentally retarded, hard of hearing, deaf, speech impaired, visually handicapped, seriously emotionally disturbed, orthopedically impaired, other health impaired, deaf-blind, or multihandicapped, or who have specific learning disabilities.

It should be noted that not all students who are termed "handicapped children" (having one of the labels listed above) are developmentally disabled or substantially handicapped. The Council estimates that as many as 20% of the students enrolled in special education programs in Alaska are students who may be substantially handicapped. The likely categorical labels of exceptionality which may indicate that a student is developmentally disabled include all of these categories except speech impaired and learning disabled.

Special Education Instruction Modes

Special education instruction can be provided in a number of ways, depending on the individual needs of the child. The child may have his/her need met by one or a combination of these models:

1. Full-time placement in a regular classroom with outside consultation provided to the regular classroom teacher so that (s)he can work with the exceptional child.
2. Regular classroom placement with supplementary teaching, tutoring, or treatment being provided to the child either in the regular classroom or elsewhere (e.g., in the office of the speech therapist).
3. Regular classroom placement and assignment for several periods per day in a "resource room" run by a special education teacher for children with one or more types of handicap.
4. Placement part-time in a regular classroom and part-time in a special education classroom.
5. Full-time placement in a special day school for the handicapped.
6. Placement in a hospital school.
7. Placement in a hospital or treatment centers.
8. Placement at home with services provided by a visiting tutor.

This "cascade of services" model describes the hierarchy of services, ranking programs in descending order of restrictiveness. One warning about applicability of this model is in order. "The model described as the most restrictive special education placement segregated institutional or home placements. However the intent of both P.L. 94-142 and Section 504 [of the Vocational Rehabilitation Act] is clearly to prohibit, for almost all purposes, segregated placements in special schools or institutions or the home; very few students truly need such placement." (Pullin, 1982)

Related Services

As noted above, handicapped children are entitled not only to appropriate special education instruction but also to related services which assist them to benefit from special education. Related services are developmental, corrective, or supportive services which assist a child to benefit from special education. Related services include, but are not limited to:

1. Transportation.
2. Speech pathology.
3. Audiological services.
4. Psychological services.
5. Physical therapy.
6. Occupational therapy.
7. Recreation.
8. Early Childhood assessment and evaluation or identification.
9. Counseling.
10. Diagnostic medical services.
11. School health services.
12. Parent counseling and training.
13. Artistic, musical, or dance therapy.

The limits of the right to related service remain largely undefined. Not all related services are necessary for every handicapped student. As is the case with other program and placement decisions, determinations about related services must rest upon assessments of the need to provide support so that students may benefit from regular special education services. To have available a wide range of related services may require that a school employ, either permanently or on a consultative basis, different types of certified personnel-school social workers, psychologists, nurses, medical doctors, speech therapists, physical therapists, occupational therapists, and others. While some of these services may not be purely educational in nature, they must be provided to ensure a handicapped child's right to an appropriate education. The child's IEP, the key to his/her appropriate education, must contain a statement of all services needed by the child. For example, a child who has impaired motor functioning due to cerebral palsy and who, as a result cannot easily manipulate a pencil requires special help through a service such as occupational therapy. Failure to provide such essential services would be a denial of the child's right to an appropriate education even though the child might receive adequate academic instruction.

Post-Secondary and Adult Education

A substantially handicapped person's need for education does not end with separation from the public school system. Like most people, substantially handicapped people require life-long learning experiences to maintain and expand competencies and develop new skills. Post-secondary and adult education are two activities which can meet some of these life-long learning needs for substantially handicapped adults.

Post-Secondary Education

Post-secondary education includes technical and/or academic instruction in subject areas that generally lead to eventual employment. Post-secondary education is provided by such educational institutions as community colleges, universities, and vocational technical schools. Some people with substantial handicaps, especially those who are mentally alert, have a need for education and training after high school. Alaska has a system of universities and community colleges and a vocational-technical school which can provide these types of educational opportunities for substantially handicapped people. In some cases, persons with substantial handicaps may require personal and/or material support assistance in order to avail themselves of opportunities for post-secondary education.

Adult Education

Another component of life-long educational opportunities for persons with substantial handicaps is adult education programs. This service differs from post-secondary education programs in that adult education may not necessarily be academically- or technically-oriented toward the goal of developing career skills. Adult education programs are typically non-academic educational opportunities in areas of special interest. For people with substantial handicaps, there may be a need to design adult education course offerings with the interests and needs of this particular population in mind. For example, an adult education offering that may be of particular interest to people with substantial physical handicaps may be how to make their living environment adapted to their special needs. Adult education programs can be a source of recreational possibilities for people with substantial handicaps by offering such recreational courses as "wheelchair basketball" or other outdoor recreation course offerings which teach people how to use adaptive equipment to enjoy outdoor sports such as skiing, mountaineering, and canoeing.

Vocational Services

"Vocational services" is the term applied to the activities which assist a person in preparing for, securing, and maintaining employment. Some of the services are geared to school-age children; others are more appropriately geared to adults. People with substantial handicaps need the same basic set of career and employment-oriented services as does the general population. The focus and intensity of services provided to people with substantial handicaps may be a bit different from those provided to the general population, but the goal of using these services remains the same: employment.

Career and Vocational Education

Career education is an organized approach to general education which emphasizes career development and incorporates career awareness, exploration, planning and decision-making, and preparation for job entry, further training and/or further education.

Vocational education provides the student with knowledge and skills which are unique to, and a requirement for, job success in a particular occupation. Vocational education on the post-secondary level addresses preparation for employment in those occupations which require other than a baccalaureate or advanced degree for job entry.

Most career education for students in public schools is begun in the elementary grades with such activities as trips to fire stations and water treatment plants, talks from people having various types of jobs about what their work is like, and other awareness activities which are designed to provide students with ideas of the wide range of career options which might be available to them. At the secondary level, career education may include activities such as "career days" in which adults from the community come to the school to share their experiences with students in either a group or one-to-one setting. Career aptitude testing may also be part of secondary career education activities, intended to help students identify their career-related strengths and weaknesses.

For students with substantial handicaps National research indicates that career education is valuable. This literature also suggests that it is very important for children with substantial handicaps to be exposed to career education activities at an early age so that there is adequate time to provide the necessary instruction to help these students. They often need extra assistance to develop awareness and skills which lead to successful additional training or employment once they are separated from the public school system.

Vocational education for students with substantial handicaps is considered part of special education services. If a handicapped students expresses an interest in pursuing vocational-related courses in his/her secondary school years, it is the legal responsibility of the local school district to make accommodation for that student's full participation in vocational education classes.

Vocational Evaluation

Vocational evaluation is the process of assessing a substantially handicapped person's capabilities to determine his or her employment potential. Another purpose of evaluation services is to establish the parameters of a person's mental or physical capacity within which an occupational choice can be made. This type of service may be provided by a trained vocational rehabilitation counselor/evaluator in settings such as specialized rehabilitation facilities. Another method is to test the capabilities of the substantially handicapped person in a short-term real work setting.

In Alaska, people who seek the services of the Division of Vocational Rehabilitation (DVR) must under go vocational evaluation. These services are a means of determining the aptitudes of a person who may be accepted for employment-related services offered by DVR. Evaluation can range from a short-term screening and examination of past employment history to a fairly extended process (up to 18 months) where a person is placed in a specialized setting such as a sheltered workshop or rehabilitation facility to evaluate individual vocational potential over time. For the most part, people who wish to receive these services travel to one of the largest Alaskan cities or, in some cases, to a facility outside the state.

Pre-Vocational Training

Pre-vocational training is instruction and practice in activities which are prerequisites to successful vocational training and employment. Some of the specific activities which are considered part of pre-vocational training include work experience; training in the basic academic skills of reading, arithmetic, and writing; work training; and, development of production speed sufficient to meet the demands of competitive industry.

Some pre-vocational training activities may be provided by local school districts as part of their vocational education curricula. Training can also be given through "work activity centers" or "sheltered workshops." These facilities are designed to provide substantially handicapped adults with skills which are prerequisites to actual vocational training and/or employment. In Alaska, there are a limited number of work activity centers and sheltered workshops located in the central, south central, and southeast areas of the state. Substantially handicapped adults who desire these services move to the communities where the services are offered and stay in a residential setting such as a boarding home or group home while they are enrolled.

VOCATIONAL SERVICES

	Recommended Service Per Level of Community			
Service	I	II	III	IV
Career and Vocational Education	L	L	L	L
Vocational Evaluation			L	L
Pre-Vocational Training	L	L	L	L
Vocational Counseling	I	L	L	L
Vocational Training			L	L
Vocational Placement			L	L
Vocational Follow-Along			L	L

L = Locally Available   I = Itinerant Service

Source: Governor's Council for the Handicapped and Gifted, 1983.

Vocational Counseling

During vocational counseling, vocational counselor evaluates a person's vocational potential and the health, social, and personal problems which may be related to a person's taking positive steps to satisfactory employment. The vocational counselor works with the substantially handicapped person to assist him/her in developing an understanding of his capabilities and limitations; in selecting a suitable vocational goal, and in using appropriately the medical services, training, and other rehabilitation services needed to achieve the best possible vocational goal.

In Alaska, DVR is the State agency which provides these services, either through permanent employees or under contract with a private firm. For the most part, villages, subregional, and regional centers receive these services on an itinerant basis, with professionals visiting various communities on a scheduled basis. A person who has been accepted for services from DVR may receive counseling services at the same time that he/she is undergoing evaluation or receiving other services from DVR. The DVR counselor (or private individual under contract to DVR to provide services) is the link to the system of services throughout a person's association with DVR.

Vocational Training

Vocational training prepares substantially handicapped persons for employment. The focus of vocational training is the acquisition of specific skills which are necessary to be successful in paid employment.

Local school districts provide some vocational training courses (such as development of clerical and mechanical skills) through their vocational education curricula, generally offered during high school years. Post-secondary educational facilities such as "vocational centers" or "vocational technical schools" and community colleges also offer specific vocational training programs. Finally apprenticeship programs teach various skilled trades.

For people with substantial handicaps, vocational training opportunities may need to include additional special services that enable the substantially handicapped person to benefit from the particular service. For example, a vocational center which offers a training course in clerical skills may wish to make physical accommodation for equipment necessary to meet the needs of people in wheelchairs. A course may need to be lengthened to accommodate the extended learning time needed by people with mental retardation. There are some specialized facilities in the state, known as sheltered workshops and vocational programs for the handicapped, which provide vocational training programs specific to the population of people with substantial handicaps. These facilities, at the present time, are generally geared to the needs of people whose primary handicap is mental retardation. People who have other substantial handicaps often seek specialized vocational training in a facility outside the state which caters to the vocational training needs of these particular populations.

Vocational Placement

Vocational placement involves developing contacts in the competitive employment market which will accept the placement of well-qualified applicants who happen to be substantially handicapped; preparing the person seeking employment with necessary interviewing skills; and, brokering between a potential employer and the client to assure that perceived difficulties to job placement can be overcome.

In Alaska, these services are again primarily provided by DVR for people with substantial handicaps. DVR also serves people who are mildly handicapped and who probably have a much better chance at being considered a "success" according to the primary DVR eligibility criteria: feasibility for employment. In practice, there are some people with substantial handicaps whose vocational potential is extremely limited in Alaska at present. For these people, sheltered workshops in Anchorage, Fairbanks, Juneau, and Ketchikan offer alternatives to competitive employment. The Anchorage program is the only sheltered workshop which offers a remunerate work program designed for long-term vocational needs.

Vocational Follow-Along

Assuming that a person with a substantial handicap has been evaluated, trained, and placed in an adequate employment situation, it is still very desirable to provide vocational follow-along services to ensure that he/she is making adequate adjustment to the work situation. Vocational follow-along services are designed to ensure successful job placement. The services may be of short duration or for an extended period of time, depending on the needs of the particular individual and the work setting. The vocational counselor takes responsibility for assisting the substantially handicapped person and his/her employer to work out adjustments that may be necessary for successful long-term employment.

Enabling Services

Enabling services assist substantially handicapped persons and their families to have information and access to services; provide assurances that the services are appropriate to individual needs; and, provide remedies for persons for whom necessary services are not provided or whose competencies need to be protected. These services are necessary components of other services discussed above, they need to occur across individual programs to assure that substantially handicapped persons and their families are receiving a comprehensive set of services which are tailored to individual needs.

Case Management Services

Case management services those provided to an individual substantial handicapped person and those aimed at the "system" of services which may be needed by people with substantial handicaps and their families.

Case management as an individualized service consists of face-to-face counseling resulting in the determination of needs, the development of a plan, the allocation of responsibility for implementation of the service plan, and ongoing monitoring of the plan. Case management implies a cooperative and collaborative working relationship between the individual and those providing services.

The above definition does not imply that there necessarily needs to be a separate service known as "case management" available to a substantially handicapped individual. However there must be at least one person who is responsible for developing a special relationship with a substantially handicapped person. This person should arrange for other services that the disabled person may need and trouble-shoot in cases where the services that a person is receiving may not be meeting his needs.

On a "systems" level, case management services are intended to ensure that all services are working together to complement the basic needs of people. However, case managers who merely advise and refer people to services, or identify the need for services whether or not they exist or can be obtained plan a weak role compared to those who have funds with which to purchase services on behalf of a disabled person.

In Alaska, there are elements of individual case management in the provision of all services offered to people with substantial handicaps. There is a "client program manager" hired by the Division of Mental Health and Developmental Disabilities whose responsibility it is to approve people for eligibility for community developmental disabilities services or admission to Harborview Developmental Center. People who receive vocational rehabilitation services have the vocational rehabilitation counselor assigned to their case as their case manager. If a person needs protective services, his/her case manager is the social worker employed by the State Division of Family and Youth Services. In some cases, local professionals handle coordination activities formally or informally, but there are no established procedures for system wide case management.

Guardianship Services

Guardianship is a legally-created relationship between a competent adult (the guardian) and any minor child or a handicapped adult. The relationship gives the guardian the legal right and the legal responsibility to act on behalf of the ward in making decisions affecting his or her life or property. Parents are the legal guardians of their children until their children reach age 18. After the eighteenth birthday, a handicapped person legally is an adult and can sign contracts and is responsible for handling his or her own finances, giving consent for medical treatment, and so forth. If the person lacks understanding or is unable to make or communicate responsible decisions about his or her care or well-being, then parents or other responsible adults can file a petition in court asking that they be named as legal guardian or ask that a legal guardian be named. While a guardian has legal rights and responsibilities for the incapacitated person, the guardian is not financially responsible for his or her support or for paying for the needed services. Guardianship in Alaska may be either "complete" or "partial."

ENABLING SERVICES

	Recommended Service Per Level of Community			
Service	I	II	III	IV
Case Management	I	I	L	L
Guardianship	L	L	L	L
Staff training/manpower development	L	L	L	L
Information and Referral	L	L	L	L
Protection and Advocacy	I	I	L	L

L = Locally Available I = Itinerant Service

Source: Governor's Council for the Handicapped and Gifted, 1983.

Staff Training and Manpower Development Services

Staff training and manpower development services promote high-quality skill levels in service providers. These activities can take the form of pre-service or in-service training for staff, updating of credentials for certain occupation categories (educators and health personnel are common categories), making available seminars or workshops on topics of new knowledge or practice in a particular field, and so forth.

Providing ongoing training opportunities and requiring certain levels of competencies for the staff are extremely important. There has been a burgeoning of new practices in the fields of professional disciplines which provide services to people with substantial handicaps. In order to refine skills and keep staff current on best practices and treatment procedures, manpower development and staff training activities are extremely important.

Information and Referral Services

All substantially handicapped people and their families need information and referral so that they will know what services are available and how to obtain them. Information and referral services can be provided by an information and referral agency, by provider agency personnel as a function of their positions, and/or by neighbors and friends who may know about services.

Protection and Advocacy Services

Protection and advocacy services provide assistance in receiving services and administrative, legal, or other remedies when services which are needed and for which the substantially handicapped person is eligible are not being provided. Protection and advocacy services include information on services and the legal rights of people with handicaps; referral and brokering for services (acting like a case manager); assistance in seeking remedies when services are not forthcoming; and, training on self-advocacy.

In Alaska, Protection and Advocacy for the Developmentally Disabled is responsible for providing these services to people with substantial handicaps and their families. The services are offered through three regional offices, with itinerant services available to rural areas.

CHAPTER 5

THE NORTHERN REGION

Demographics

The Setting

The Northern Region of Alaska, the North Slope Borough, extends the width of the state and is entirely above the Arctic Circle. Its 88,281 square-mile area is larger than 39 states. Barrow is the major settlement and the regional center for the other seven villages. It is also the farthest north established city on the North American continent. (North Slope Borough Health and Social Services Agency, 1982)

The Nórth Slope Borough was organized in 1972 as a first class borough and is geographically the largest single municipality in the world. In 1973, a second election converted the Borough to a home rule charter, the strongest form of local government allowed under the United States Constitution. (North Slope Borough Health and Social Services Agency, 1982)

The North Slope is generally accessible to the rest of Alaska and the world only by air travel. Barrow is 502 air miles from Fairbanks and 722 air miles from Anchorage; daily jet services link Barrow to both cities. Smaller aircraft provide scheduled and charter services from Barrow to the other seven villages, weather permitting. Other means of transportation include barges and the BIA North Star during the ice-free months and snowmachines and dogsleds in the winter. Motor vehicle access is possible via the Dalton Highway between Livengood and Prudhoe Bay, but this road does not pass through any of the villages. (North Slope Borough Health and Social Services Agency, 1982)

The People

The Inupiat (northern Eskimo) people and their predecessors have occupied Arctic Alaska for thousands of years. Inupiat remain the majority of the population, although significant numbers of non-Natives have moved to the North Slope in conjunction with the oil and gas boom.

Most people in the northern region live in the traditional communities of Anaktuvuk Pass, Atqasuk, Barrow, Kaktovik, Nuiqsut, Point Hope, Point Lay, and Wainwright. The Prudhoe Bay area is an industrial enclave comprised of numerous more or less self-contained company facilities; there are also military establishments associated with the DEW-Line. Very few people live in other areas of the region, although people commonly move to and from hunting camps from which they conduct subsistence activities.

The North Slope's 1982 census counted a total of 12,729 people, 8,036 of whom were located in three oil and gas-related work sites and seven military installations. Table I in Appendix A depicts this total population of the North Slope for 1980 and projected to 1984 and 1988. Because most of the people who live at the petroleum work sites and the military installations are young adult males who do not have their families with them, their communities are very unlike the traditional villages. Most of these people are non-Native; there are very few among them who are aged 0-20 or 65+. When someone becomes ill or disabled, he leaves the area, usually to return to his home community, which may be far from Alaska. Therefore, for the purposes of planning for services for the handicapped, the oil and gas developments and military installations should be omitted from consideration.

Only the 4,693 North Slope people residing in the seven traditional villages should be counted for purposes of planning for services for the handicapped. The population figures presented in Table 5-1 should be used to predict service needs by location. Table 5-2 provides a summary of the North Slope Borough's permanent resident population by village as of July 1, 1982.

The Economy and Culture

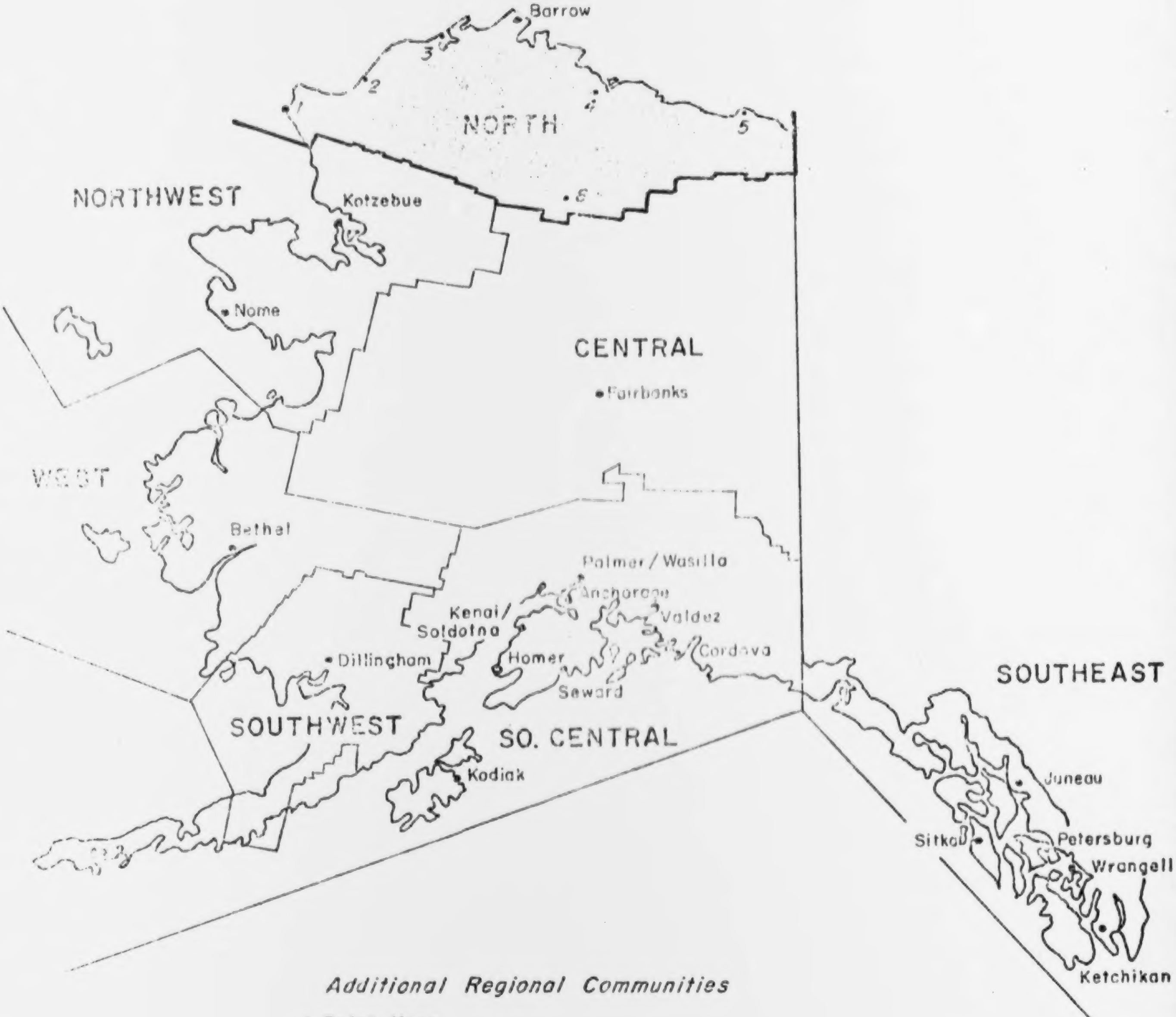
The North Slope has experienced a series of boom-bust cycles, first with the coming of the New England whaling ships and most recently with the oil pipeline. Oil revenues have enabled the Borough to undertake an extensive capital improvement program designed to provide many of the services and amenities of modern life. The petroleum industry itself and related construction of the camps and capital improvements in the villages have created many opportunities for cash employment. The third largest source of jobs is government, with the majority of positions in local and state government. Work associated with the petroleum activities is located primarily outside of the traditional villages; contract construction jobs are available both in and outside traditional communities. Most government positions are located in Barrow; employment opportunities within the other villages are few.

On the whole, the labor force in the northern region is highly skilled. However, a great disparity in skill levels exists between the resident Native population and non-resident workers. In recent years, job-training programs have raised the skill levels of the Native population, but unemployment and underemployment comprise a serious problem, particularly in the smaller villages. Job opportunities peak in late summer and early fall and reach seasonal lows in mid- to late winter.

In spite of recent economic opportunities, the Inupiat people continue to depend on subsistence activities. During the extreme fluctuations in economic opportunities that have become typical of the region, the Inupiat have retained strong ties to the land. Their resource use patterns are determined by custom and not by Western ideas of land ownership. Today, high prices, high unemployment, and limited economic opportunities make subsistence activity a necessity for many people.

Traditional cultural values that accompany subsistence activities are important to the Inupiat. Communities and families were, and continue to be, organized around whaling and hunting. The continued practice of subsistence lifestyles is the very cornerstone or the Inupiat culture. (North Slope Borough Health and Social Services Agency, 1982)

NORTH REGION


Barrow
NORTH
NORTHWEST
Kotzebue
Nome
CENTRAL
Fairbanks
WEST
Bethel
Palmer / Wasilla
Anchorage
Kenai/ Soldotna
Valdez
Cordova
Homer
Seward
Dillingham
SOUTHWEST
SO. CENTRAL
Kodiak
SOUTHEAST
Juneau
Sitka
Petersburg
Wrangell
Ketchikan
1
2
3
4
5
6

Additional Regional Communities

1 Point Hope
2 Point Lay
3 Wainwright
4 Nuiqsut
5 Kaktovik
6 Anaktuvuk Pass

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TABLE 5-1

VILLAGE POPULATION OF THE NORTHERN REGION BY AGE GROUP, 1980 and PROJECTED TO 1984 and 1988

Age Group	1980	1984	1988
0-2	275	324	361
3-5	214	253	281
6-20	1,265	1,493	1,660
21-64	2,297	2,710	3,013
65+	148	174	194
TOTAL	4,199	4,954	5,508

Sources:

U.S. Department of Commerce, Bureau of the Census. 1980 Census of Population, General Population Characteristics, Part 3 Alaska. PC80-1-B3 Alaska. Washington, D.C. August, 1982. pp. 3-56 - 3-57.

North Slope Borough. Population for villages excluding Barrow and Point Lay, census conducted by village coordinators in accordance with guidelines laid down by the State Demographer. July 1, 1982.

North Slope Borough. Barrow population derived from established relationships between residential electric utility connections and dwelling units, using methodology accepted by the State Demographer. July 1, 1982.

North Slope Borough. Point Lay population enumerated in January/February 1982 as part of a State-supervised North Slope Borough special census. 1982.

TABLE 5-2

1982
NORTHERN REGION VILLAGE POPULATIONS AND COMMUNITY LEVELS

Village	Community Level	Population
Anaktuvuk Pass	I	215
Atqasuk	I	210
Barrow	III	2,647
Kaktovik	I	189
Nuiqsut	I	302
Point Hope	I	544
Point Lay	I	105
Wainwright	I	465
TOTAL		4,677

Sources:

North Slope Borough. Population for villages excluding Barrow and Point Lay, census conducted by the village coordinators in accordance with guidelines set by the State Demographer. July 1, 1982.

North Slope Borough. Barrow population derived from established relationships between residential electric utility connections and dwelling units, using methodology accepted by the State Demographer. July 1, 1982.

North Slope Borough. Point Lay population enumerated in January/February 1982 as part of a State-supervised North Slope Borough special census products. The continued practice of subsistence lifestyles is the very cornerstone of the Inupiat culture.

Social Problems

Rapid change faced by the Inupiat and the presence of a large transient population of young men contribute to significant social problems. Alcohol abuse is particularly serious in the northern region. A number of illicit drugs are also readily available and widely used, especially among the young. Most crime is directly related to substance abuse. In recent years, the area has also witnessed a large increase in the number of attempted suicides, and the number of people hospitalized for mental illness was one of the largest in the state. Domestic violence and child abuse/neglect are also on the rise. (Northern Alaska Health Resources Association, 1982)

The Target Population

The two major categories of disabilities are "developmental disabilities" and "other disabilities." There are many criteria used to determine whether particular conditions are truly functionally limiting, or disabling, and there are various definitions about what constitutes a developmental disability. These terms and guidelines are described elsewhere in this report.

In simple terms, a "developmental disability" is a condition which arises prior to an individual's twenty-second birthday and which greatly affects the way in which he grows and matures. The kinds of conditions which may cause developmental disabilities include mental retardation, sensory impairments, cerebral palsy, autism, or orthopedic problems. For practical purposes, almost any substantial physical or mental problem occurring in childhood, and having a pervasive effect on the individual's functional abilities and need for service constitutes a developmental disability. Therefore, all children with substantial handicaps and all adults with such handicaps which arose before they were 22 years old are considered to be developmentally disabled.

"Other disabilities" are all those substantial impairments which have onset in adulthood. Even if two people's impairments are identical, such as with blindness or paraplegia, the disabled person whose problem arose after age 22 would not be considered developmentally disabled. Also with adults, degree of disability is determined by limitations in activities of daily living. A computer programmer who loses his legs in an accident might not be substantially functionally impaired, whereas a construction worker would be. All these factors must be taken into account when "other disabilities" are described.

As stated, all children who are substantially impaired are developmentally disabled. These people make up about 3% of the age groups 0-2 and 3-5 and 1.87% aged 6-20. Adults are counted among the developmentally disabled only if their impairments arose in childhood. On the average, 1.49% of the population aged 21-64 and .5% aged 65+ are developmentally disabled. In addition, about 1.90% of the people aged 21-64 and 10% aged 65+ have other substantial limitations.

Table 5-3 summarizes the number of North Slope residents with substantial disabilities. Altogether, there were approximately 73 developmentally disabled and 62 otherwise disabled people in 1980. By 1988, those numbers are expected to rise to 94 and 76 respectively. Forty-nine will be among the school-aged (3-20) population.

Explanations of functional limitations in the seven major life activity areas such as mobility, self-direction and economic self-sufficiency and regional estimates of people with limitations in each of the seven areas are included in Chapter Two.

TABLE 5-3

NORTHERN REGION ESTIMATED POPULATION OF PERSONS WITH SUBSTANTIAL HANDICAPS, 1980

	Persons with Substantial Handicaps		
Age Group	Developmentally Disabled	Other	Total
0-2	8	0	8
3-5	6	0	6
6-20	24	0	24
21-64	34	47	81
65+	1	15	16
TOTAL	73	62	135

Sources: 1980 Census, 1981 DD State Plan, Report of Comprehensive Service Needs Study by Urban Institute, 1975, Division of Vocational Rehabilitation, Older Alaskans Commission.

Methodology: See Appendix.

Community Descriptions

Traditional Villages

For purposes of this plan, the North Slope Borough is comprised of eight traditional villages. Barrow, a Level III community, is the largest village, with 2,647 people in 1982. Barrow serves as the governmental and service center for all of the North Slope Borough and is a major transportation hub for the region. Approximately 79% of Barrow's population is Native; about 42% is under the age of 21. (U.S. Department of Commerce, Bureau of the Census)

Barrow has many of the features of any small town. It has a bank, a dry cleaners, a gas station, a yard-goods store, and a beauty salon. There are four general stores carrying food stuffs, clothing, hardware supplies, and household goods. Barrow also has four restaurants. The radio station, KBRW, broadcasts across the Slope, covering local events live. It is also used to send messages to and from families and friends in other villages, at fish camp, and out hunting. Barrow has seven churches, a fire department, and a teen center. (North Slope Borough Health and Social Services Agency, 1982)

In other respects, Barrow remains undeveloped. Many people still live in older houses without flush toilets and running water. Privately-owned water trucks bring water from the treatment plant for those who order it; other people cut blocks of ice to melt for water. A honey bucket truck collects human wastes. New housing is limited, and rents are high. (North Slope Borough Health and Social Services Agency, 1982)

As the regional center for the North Slope, Barrow maintains a modern airport which handles daily flights to Anchorage and Fairbanks as well as numerous scheduled and charter flights to the surrounding villages. Barrow is also headquarters for the North Slope Borough School District; the North Slope Borough Health and Social Services Agency, which provides human services for the region; and, the Barrow Public Health Service Hospital, which offers primary acute care and obstetrics services.

The seven Level I communities look to Barrow for health, education, and social services, and transportation beyond the Borough. With the exception of Anaktuvuk Pass, Point Hope, and Kaktovik residents, villagers usually travel to Barrow for hospital care. All villages receive itinerant services from Barrow. Because of its geographical location, Point Hope often orients to Kotzebue.

Anaktuvuk Pass is the only "inland" village on the North Slope, lying on the Continental Divide in the Brooks Range. Anaktuvuk Pass is culturally somewhat different from the coastal villages, reflecting different subsistence patterns. The village is 223 air miles north of Fairbanks and 293 air miles south of Barrow. Wien Air Alaska contract bush flights and Air North link Anaktuvuk Pass to Bettles and Fairbanks daily except Sunday. Anaktuvuk Pass is 92% Native in population, with 215 residents in 1982. These people have cited needs for year-round water and sewage systems; increased dental service; health education related to alcoholism, drugs, and hygiene; itinerant optometric services; congregate meals for seniors; and, homemaker services.

Atqasuk, with 210 people, is 58 miles southwest of Barrow on the Meade River. It is 96% Native in population. Like Anaktuvuk Pass residents, Atqasuk's people have asked for increased dental service; health education; optometric visits; congregate meals for seniors; and, homemaker services.

Kaktovik is the easternmost North Slope village, located 310 miles southeast of Barrow on the Arctic Ocean. Kaktovik is on Barter Island, by which name the area is more generally known. The village is 89% Native and has the second smallest population in the Borough -- 189 people in 1982. Needs in Kaktovik are basic, with year-round sewage and water systems heading the list. The residents cite the same kinds of needs as do the other villages. Wien Air Alaska contract bush flights and Air North serve Barter Island through Fairbanks and Fort Yukon five times weekly.

Nuiqsut, with 302 residents, lies on the coast about halfway between Barrow and Kaktovik, near the mouth of the Colville River. The village is 92% Native. Residents' major needs are in the areas of water and sewage and fire protection.

Point Hope is the second largest village in the North Slope Borough, with 544 residents in 1982, 95% of whom were Native. Point Hope lies on the Chukchi Sea northwest of Kotzebue. Because of its location, it looks to Kotzebue and the Maniilaq Association for some health and social services and to the Kotzebue Public Health Service Hospital for inpatient care. Point Hope is technically a part of the North Slope Borough, however, and so receives some human services out of Barrow and educational services through the North Slope Borough School District. Residents often flow through Kotzebue to Anchorage for major medical services. Wien Air Alaska flies to Point Hope via bush planes through Kotzebue six times weekly.

Point Lay, located on the Chukchi Sea north of Point Hope, is the smallest village on the North Slope. Its 1980 population of 105 was 89% Native. Point Lay residents cite needs for increased dental care; health education; optometric visits; and homemaker services.

Wainwright, with 465 people, is 100 air miles southwest of Barrow on the Arctic coast. It is linked by Wien Air Alaska bush flights to Barrow four days per week. Wainwright's population is 97% Native.

Service Flow Patterns

As described above, Barrow is the primary service community for all of the North Slope, especially for governmental services. For certain kinds of services, particularly health care, Point Hope orients to Kotzebue; similarly, Anaktuvuk Pass sometimes looks directly to Fairbanks.

For specialized diagnostic and treatment services, Native residents almost always travel to Anchorage. This pattern exists because of established air routes and also because the Alaska Native Medical Center is in Anchorage. With increasing restrictions on contract care by the Indian Health Service, use of the Anchorage facility will become even more frequent as services at Fairbanks Memorial Hospital are disallowed.

Available Services

Health Services

In 1977, the Inupiat Community of the Arctic turned over all health care delivery responsibilities to the North Slope Borough Health and Social Services Agency (NSBHSSA). Since that time, the Agency has contracted with the State to provide all services previously delivered by the Division of Public Health and the Division of Family and Youth Services. The Agency also administers grant funds from the State Office of Alcohol and Drug Abuse, the Division of Mental Health and Developmental Disabilities, the Office of Emergency Medical Services, and other sections of State government. Today, the NSBHSSA operates over twenty programs. Their funding comes from the Indian Health Service, federal and state contracts, and Borough taxes.

Some of the Borough's human services are located in Barrow in the Inuit Ikayuqtisigviat, also called the Greist Family Service Center. Here the mental health program provides emergency and ongoing outpatient therapy. The Eye Care Center offers optometric supplies and coordinates eye clinics throughout the Slope. Two dentists staff the dental clinic and take turns holding clinics in their other Slope villages. Alternative Programs for Young People have their office in the Greist building, as do the Public Assistance Programs, the two public health nurses, and the State social service programs.

The Matsutani Building in Barrow is the center for administrative services for the Health Department and coordinators for Emergency Medical Services, Health Education and Media, the WIC Program, Parent/Infant Program, the Children's Receiving Home, and Arctic Women in Crisis.

The Community Health Aides (CHA) program is administered out of Barrow. Each village has at least one CHA, who provides preventive and primary health care services. CHAs provide the only locally-based health care services in most villages and are an important link between the Barrow Hospital and local health care needs.

The Barrow Public Health Services (PHS) Hospital has a 13-bed inpatient facility in one wing and a daily outpatient clinic in the other wing. Three physicians see patients at the clinic and in the hospital. Services are generally limited to primary acute care, obstetrics, and minor surgery. Patients requiring more sophisticated services are sent to Fairbanks or Anchorage by commercial airlines or medevaced (emergency evacuation for medical care) by Lear jet.

The village health aides have two-way radio contact with the Barrow Hospital. Each village has a certain time each day to make routine reports; in case of an emergency, they can call in any time. Physicians who oversee the work of the CHAs can order a medevac or advise the CHA about procedures or medications.

The Barrow PHS Hospital, as the only medical facility on the Slope, is open to both Natives and non-Natives. Similarly, other programs funded by the State and Borough serve everyone. (North Slope Borough Health and Social Services Agency, 1982)

Table 5-4 outlines the health services provided on the North Slope by village. Other than services rendered by CHAs, all health care in the Level I communities is provided on an itinerant basis. At this time, there is no occupational or physical therapy or home health care provided anywhere on the Slope.

Support Services

Support services are those services which are needed in addition to adequate medical services, educational and vocational services, and employment opportunities in order for a substantially handicapped person to live independently or with his/her family. There are three major types of support services - maintenance services, living skills training services, and material support services.

Maintenance Services

The North Slope lacks most services which are commonly considered "maintenance" services except on an informal basis. There is no day care assistance program on the North Slope and no licensed day care center, although one is in the planning phase. Respite care, for which approximately eight families have a need, is unavailable. Homemaker, home health aide, home health nursing, and personal aide and attendant services do not exist in this region. Transportation services are not provided except for senior citizens in Barrow and, as needed, by the North Slope Borough School District. Recreational opportunities are minimal, and no special services are available for handicapped people other than through the School District's special education program. The Special Olympics program operates informally through community sponsors.

Developmental Services

There are no developmental or living skills training programs available on the North Slope other than activities through the School District's special education program. Some training takes place informally through the village health aides, public health nurses, and others. The Parent/Infant Program provides parent training for children under age 3 (discussed in the Education Services section).

Material Support Services

Cash assistance is available to eligible individuals and families on the North Slope on the same basis as elsewhere in the state. The major categories of special assistance to the handicapped are Aid to the Disabled and Aid to the Blind, through the State's Division of Public Assistance, and Supplemental Security Income (SSI) payments, in accordance with the federal Social Security Act.

TABLE 5-4

HEALTH SERVICES AVAILABLE IN THE NORTHERN REGION OF ALASKA,
by COMMUNITY, 1983

		Prevention					Early Identification											
Community	Level	PC	SHE	PA	WCP	I	PNT	MDS	VHS	MTS	D&E	MS	DS	OT	PT	SSH	HHN	HHA
Anaktuvuk Pass	I	L	L		L	I			I			I	I			I		
Atqasuk	I	L	L		L	I			I			I	I			I		
Barrow	III	L	L		L	L	L	L	L	L	L	L	L			L		
Kaktovik	I	L	L		L	I			I			I	I			I		
Nuiqsut	I	L	L		L	I			I			I	I			I		
Point Hope	I	L	L		L	I			I			I	I			I		
Point Lay	I	L	L		L	I			I			I	I			I		
Wainwright	I	L	L		L	I			I			I	I			I		

I = itinerant L = locally-based

PC = Prenatal care
SHE = School health education
PA = Public awareness
WCP = Well-child program
I = Immunizations
PNT = Prenatal Testing

MDS = Medical/developmental screening
VHS = Vision and hearing screening
MTS = Metabolic screening
D&E = Diagnosis and evaluation of handicapping conditions
MS = Medical services

DS = Dental services
OT = Occupational therapy
PT = Physical therapy
SSH = Speech and hearing services
HHN = Home health nursing
HHA = Home health aide services

Sources: Northern Alaska Health Resources Association. Health Resource Development Plan for Northern Alaska, 1982. Fairbanks, Alaska. April, 1982.
North Slope Borough Health and Social Services Agency. Tribal Specific Health Plan, North Slope Borough. R.A. Hodge and Associates. Spokane, Washington. 1979.

Personal adaptive equipment such as wheelchairs, braces, hearing aides) can be provided to disabled children through Alaska's Handicapped Children's Program. Personal adaptive equipment for adults and environmental adaptive equipment (housing adaptations such as ramps, grab bar, special furniture, lifts) for people of all ages are generally unavailable except through private or third-party payment or informally.

Residential Services

Services Available in the Northern Region

Most disabled people from the North Slope, as everywhere else, live in their own homes with their families. For children, living in the natural environment includes residing with parents or other relatives. It may also include foster care, adoption, or subsidized adoption. Although there currently are no developmentally disabled children on the North Slope in either foster care or adoptive placements, those options are always open. For adults, the natural environment consists of independent living arrangements with spouse and family, singly, or with friends.

There currently are no special residential services for handicapped individuals located on the North Slope. While handicapped persons may receive temporary services at the Arctic Women in Crisis shelter or the Children's Receiving Home, neither of these facilities is designed for their special needs.

Facilities Utilized by Residents of the Northern Region

During FY 1983, six substantially handicapped residents of the northern region were in residential placements outside of their home communities. Five of these people were adults aged 21-64. Two of them were placed in the Harborview Developmental Center in Valdez. The others were in Careage North in Fairbanks, Hope Cottages Adult Group Homes in Anchorage, and Access Alaska-Independent Living Program in Anchorage. The only child from the North Slope who was placed outside of his home community was in the Hope Cottages Children's Group Home in Anchorage.

Residential Service Needs of North Slope Borough Residents

Because of the small population size of the North Slope, exact delineation of the numbers of people needing residential services is difficult. There is considerable margin for error in any need projection based upon such a small group of people. However, available information indicates that approximately three people on the North Slope need augmented living environments; three need devised environments; and, three need protective environments. Of these nine individuals, six are currently placed outside of their home communities; the remaining three are not being served in terms of their residential requirements. Two of the people who are residing in protective environments are felt to be inappropriately placed according to their degree of disability. Table 5-5 summarizes residential service needs and placements for North Slope residents.

TABLE 5-5

NUMBERS OF SUBSTANTIALLY HANDICAPPED PERSONS NEEDING AND RECEIVING RESIDENTIAL SERVICES NORTHERN REGION, FY 1983

	Number of People				
Placement by Age Group	Needing Service	Receiving Service in Home Region	Receiving Service Outside Home Region	Unserved	Unserved in Home Region
AUGMENTED ENVIRONMENT					
0-5	1	0	0	1	1
6-20	1	0	0	1	1
21+	1	0	1	0	1
All ages	3	0	1	2	3
DEVISED ENVIRONMENT					
0-5	1	0	0	1	1
6-20	1	0	1	0	1
21+	1	0	1	0	1
All ages	3	0	2	1	3
PROTECTIVE ENVIRONMENT					
0-5	1	0	0	1	1
6-20	1	0	0	1	1
21+	1	0	3*	0	1
All ages	3	0	3	2	3
TOTAL	9	0	6**	5	9

* Includes two people who are inappropriately placed in protective environments.
** Includes two people who are receiving inappropriate levels of service.

Sources: Governor's Council for the Handicapped and Gifted, FY 81-82 DD State Plan. Fairbanks, Alaska. Chapter 6.
Surveys of provider agencies. January, 1983.
Analysis of special education and residential placement data. June, 1983.

Educational Services

Infant Learning Program

Infants and young handicapped children under the age of three are served by the North Slope Borough's Parent/Infant Program. Based at the Health Department in Barrow, an infant learning program teacher visits families and children in their own homes to provide instruction, training, and family education on child development and ways to stimulate the development of each handicapped or "at risk" child. The teacher makes weekly visits to the Public Health Service clinic and hospital to provide information about the Parent/Infant program, receive referrals, and review progress of the children with medical/health specialists.

The teacher travels to each of the seven North Slope villages three to four times a year and involves the Community Health Aides in the infant learning services for follow-up, family support, and providing materials.

The program plays an important part in developmental screening of children and early identification of high-risk or developmentally delayed children on the North Slope. It also insures that the children identified can begin public school programs at age three and collaborates with principals and teachers in Barrow and each village on appropriate early childhood education or pre-school programs for these children.

Significant increases in the 0-2 population, from 275 in 1980 to 598 in 1984, would double the number of children requiring screening or evaluation and the number needing regular home training services through the Parent/Infant Program.

In fiscal year 1982, of a total 0-2 population of 342 children, 97 were screened, and nine were enrolled in the Parent/Infant Program. Some 209 home visits were made, totalling 304 contact hours with families. Since FY 1982 the program has continued to serve an average of nine children on the North Slope.

Pre-School Programs

There are no Head Start programs in the Northern Region. Since the mandatory public school age for handicapped children is age 3, the North Slope Borough School District is required to begin serving handicapped children identified by the families in the Parent/Infant Program and local agencies. Once referrals are made, the school district must evaluate each child to determine eligibility and needs. Once a child is enrolled, the district develops an Individualized Education Program for each child, involving parents, teachers, and specialists in the process to make sure that appropriate services are planned and agreed upon before services begin.

Handicapped children at this age are usually served through the generic Early Childhood Education program of the school district. This program had 125 children enrolled at the end of the 1982-83 school year, with about one-half in Barrow and the balance divided among the village schools. Any three or four year old child can attend except in Barrow where space limitations have required a first-come, first-served policy. Programs vary in length from a half day, either morning or afternoon, in Barrow, to almost a full day in some of the villages.

The number of handicapped children enrolled is unknown. Estimates would range from a low of 5% of the 3-5 population, or seven children, to a high of 15%, or thirty-two children, based on 1980 population figures.

Special Education

The North Slope Borough School District had a total enrollment of 1,175 students in grades K-12 in ten schools in 1982-83. Of these, 192, or 16%, were certified and enrolled in special education programs. Forty-three were speech impaired and received speech and related services while receiving academic instruction in regular classes. One hundred thirty-one, or 68%, were classified as learning disabled (above the usual fifty per cent of special education students' statewide average) and received special instruction in regular classrooms and in resource rooms in addition to regular education programs.

Of the eighteen other special education students, four were mentally retarded, two were deaf, seven were seriously emotionally disturbed, two were orthopedically impaired, and three had other health impairments. These students required more intensive, specialized, and related services (such as physical therapy, adaptive devices, psychological services, and transportation) and were served in many different ways, depending on their individual needs, their IEPs, the particular school setting, and the availability of special education personnel. Some received full day special education services. Others received itinerant services on a weekly or monthly basis.

Four North Slope children were placed out-of-district and attended programs in Anchorage. Three, ages 16-19, were in the multi-handicapped program of the Anchorage School District and one, age 13-15, was at Jesse Lee Home.

The Council estimates that 10% of special education students may be considered "low-incidence" students because of the infrequent occurrence of their particular handicapping condition and the severity of the impairment: their location in smaller Level I or Level II communities presents particular obstacles to obtaining needed specialized services. The State's outreach service program, ARMSI, is utilized by most districts, including North Slope, to augment locally available education services with itinerant specialists who can provide consultation, evaluation, teacher training, special materials, and direct instruction.

Estimates of the number of substantially handicapped or developmentally disabled school age students are between 1.87% and 2.5% of the total school age population and 20% - 25% of the special education population. North Slope figures are consistent with these prevalence figures and generally in line with other school districts.

TABLE 5-6

NORTHERN REGION
INFANT LEARNING PROGRAM ENROLLMENT STATISTICS, FY 1982

Community	Agency	Total Pop. 0-2 FY80	Disabled Children		Screened Svd	Enrolled	T	MDE	ILP Utilization		Funding (in thousands)		
			At Risk	DD					Contact Hours	Number Home Visits	FY82	FY83	FY84
Barrow	North Slope Borough	342	17	10	97	9	1	2	304	209	48.9	48.9	64.8

DD = developmentally delayed; T = terminated; MDE = received multi-disciplinary evaluations.

Sources: Division of Public Health, Infant Learning Program Year-End Report, FY82, Anchorage, Alaska. September, 1982.
Division of Public Health, FY84 budget allocations, Infant Learning Program Coordinator. Anchorage, Alaska. August, 1983.

TABLE 5-7

1982-83 SPECIAL EDUCATION ENROLLMENT INFORMATION
NORTHERN REGION

School District	Number of Schools	Total Enrollment	Number of Sp Ed Students	% of Total Enrollment	Exceptionality											
					MR	HH	D	SI	VH	SED	OI	OHI	SLD	DB	MH	Out of District
LEAs																
North Slope	10	1,175	192**	16	4		2	43		7	2	3	131			4

** Does not include out-of-district

MR = Mentally Retarded
HH = Hard of Hearing
D = Deaf
SI = Speech Impaired

VH = Visually Handicapped
SED = Seriously Emotionally Disturbed
OI = Orthopedically Impaired
OHI = Other Health Impaired

SLD = Specific Learning Disability
DB = Deaf/Blind
MH = Multiply Handicapped

Sources: Alaska Department of Education. 1982-83 School Year, P.L. 94-142 Count. Juneau, Alaska. December, 1982.
Alaska Department of Education. 1982-83 School Year, P.L. 89-313 Count. Juneau, Alaska. October, 1982.
U.S. Department of the Interior, Bureau of Indian Affairs, Anchorage Office - Data Search. Anchorage, Alaska. May, 1983.

TABLE 5-8

1982-83 SCHOOL YEAR FUNDING FOR SPECIAL EDUCATION PUBLIC SCHOOLS NORTHERN REGION

	FY83 Funding Sources					
	Foundation Funding					
School District	Reg. Ed. Allotment	Special Ed. Allotment	Total	P.L. 94-142 Funding	P.L. 89-313 Funding	Total Funding
LEAs						
North Slope	1,386,957	986,955	2,373,412	33,130	---	2,406,542

Sources: Alaska Department of Education, Division of Education Program Support, F83 P.L. 94-142 and P.L. 89-313 Distribution Calculations, unpublished data. Juneau, Alaska. January, 1983.
Alaska Department of Education, Division of Management, Law, and Finance. Public School Foundation Program Calculations. Juneau, Alaska. March 2, 1983.

Vocational Services

"Vocational services" is the term applied to the activities which assist a person in preparing for, securing, and maintaining employment. Some of the services are geared to school-aged children; others are more appropriate for adults. People with substantial handicaps need the same basic set of career and employment-oriented services as does the general population. The focus and intensity of services provided to people with substantial handicaps may be a bit different from those provided to the general population, but the goal of using these services remains the same - employment.

Division of Vocational Rehabilitation

The Division of Vocational Rehabilitation (DVR) is the major vocational agency of Alaska State government. DVR is charged under P.L. 93-112 and A.S. 23.15.010 with providing a full range of vocational evaluation, counseling, training, job placement, and follow-along services. North Slope Borough residents receive DVR services within their region only through itinerant services to Barrow. For vocational evaluation, training, or placement in sheltered settings, Northern Region residents must travel to other parts of the state.

North Slope Borough School District

The North Slope Borough School District provides career and vocational education, pre-vocational training, and vocational training as components of the regular school curriculum. The District had 29 approved vocational education courses in the 1982-83 school term. These services and courses are provided to all interested students and are not designed especially for the substantially handicapped.

Enabling Services

Case Management Services

Informally, case management functions are carried out by particular agencies currently providing services to a disabled person and his or her family. For families involved in the Parent/Infant Program, for example, the North Slope Borough Health Department's Infant Learning Teacher is looked to for guidance, information, and advice by the families and other agencies. The teacher may also assist, with family approval, in making referrals, planning, and obtaining, other needed services. Community health aides are the local, resident village health professionals who also serve this function for many, also on an informal basis as an adjunct to health care responsibilities. Division of Family and Youth Services Social Workers also assist in case management as part of their provision of protective or other family services.

There is no formal case management "system" for people with disabilities, just as there is no such system for the general population or for other population sub-groups. For most services to be provided, however, there are requirements for individual case service planning, development of habilitation, rehabilitation, special education, or family service plans, which is the primary responsibility of the providing agency in consultation and coordination with other related service or health personnel.

Guardianship Services

Guardianship and conservatorship services for people who are disabled can only be provided for legally after following a process of filing a petition and having a hearing in Superior Court. Since guardianship, responsibility for the person and decisions for the person, and conservatorship, management of the person's finances, mean that some or all of the disabled or incapacitated person's legal rights are taken away, special legal proceedings must take place to make sure that rights are not taken away without due process and without basis.

The Second Judicial District includes the North Slope. A Superior Court Judge is at Barrow and petitions may be filed and heard there. State law provides that a visitor must be appointed to investigate the situation of the person for whom a guardian is sought, to see if guardianship is necessary to protect the individual, and to identify people who might serve as guardian. If the Court determines that guardianship is necessary and that there is no relative or friend to be guardian, the Court can assign the Public Guardian to handle the person's affairs. In Barrow, the Probate Master and Public Coroner also serves as Public Guardian.

Staff Training and Manpower Development Services

Each agency has responsibility to provide for staff training. The North Slope Borough Health Department and the Borough School District provide regular training opportunities for personnel. P.L. 94-142 requires training of teachers and other special education personnel. Title VI-B funds are provided to the school district based on special education enrollment and are utilized for training as well as child find activities. The special education outreach program, ARMSI, provides training to local people on an itinerant basis. The Division of Family and Youth Services has a training center in Anchorage for social workers employed by the Division. The Division of Public Health provides health education and training and sets aside money for annual training of infant learning program teachers. The Council has conducted surveys of individual services and included information on manpower development needs. Identified needs have been brought to the attention of the providers and to state funding agencies.

No comprehensive manpower assessment of people working with disabled individuals has been conducted on the North Slope or the other regions. The Council plans to adapt and utilize the assessment instrument developed by the Institute for the Study of Mental Retardation and Related Disabilities.

Information and Referral

In the Northern Region information about services and referral to services takes place informally and formally. Because of the small number of people living in villages and in Barrow word gets around fast about new services, new workers, and about people's impressions and perceptions of service delivery. Each service provider has a portion of the over-all responsibility to explain services, answer questions, make referrals, and coordinate with other workers and people in the community. A great deal of coordination is required because of the use of itinerant services. This means that local people must plan and coordinate schedules, trips, flights, and meetings between people in the villages such as the health aides as well as with itinerant providers who may be coming from Fairbanks, Anchorage, or beyond. At this point in time there is no over-all coordination of health and social services information and referral.

Protection and Advocacy Services

Protective services are provided by the Division of Family and Youth Services. Legal services are available on a resident basis in Barrow and on an itinerant basis to the villages by Alaska Legal Services Corporation. Private attorneys practice in Barrow and private attorney services can be obtain from Fairbanks and Anchorage. The state Ombudsman's Office in Fairbanks accepts and investigates complaints about state agencies and provides itinerant service to Barrow.

The only agency providing specialized protection and advocacy services to remedy violations of rights or due process, and to seek redress through negotiation, administrative, and legal means, and to provide assistance to disabled individuals who cannot access services themselves, is Protection and Advocacy for the Developmentally Disabled (P.A.D.D.). An advocate in Fairbanks can receive inquiries and provide services to the Northern Region on an itinerant basis. One disabled child received assistance in regard to special education services in F83.

Obstacles and Opportunities

Obstacles

Every region has characteristics of geography, economics, population size, attitudes, and values which can present challenges in human service delivery. Many of these obstacles are similar from area to area; others are unique to particular regions or villages. Almost every problem can be overcome through dedication and creativity on the part of community residents. The following obstacles to service delivery for the handicapped have been identified in the northern region:

1. The physical environment poses awesome challenges to regionwide service systems. The wide dispersal of people, long distances, and difficult travel conditions make it important to develop support competencies at the local level.

2. The small population size of the North Slope Borough, particularly outside of Barrow, causes the provision of certain kinds of services not to be feasible. There are not enough clients to share overhead costs, nor can providers maintain their technical skills with so few people to serve.

3. The North Slope has no centralized plan for regional service development. The Tribal Specific Health Plan, adopted in 1979, is outdated and was never comprehensive in terms of needs of the disabled.

4. Lack of services in the past contributed to inappropriate placements of some clients and no services for others. There are now people in residential placements outside of their home communities who could be returned if adequate support services were available. Community services are needed, especially placements in augmented environments and support services.

5. Community residents have attitudes in some cases which work against the development of local, community placements for severely disabled people. Positive attitudes and awareness of what can be accomplished locally must precede community acceptance of normalization.

Opportunities

The planning process enables communities to change obstacles into opportunities. Concerned service providers, clients, family members, and other interested people can work together to solve problems and implement community change.

Several opportunities in the area of services for the handicapped are now available in the northern region:

1. State law requires the State to plan, develop, and implement a comprehensive system of services and facilities for the handicapped (A.S. 47.80.100). Therefore, the State is obligated to assist the northern region to design and implement appropriate services.

2. The unified Borough government system, which now contracts with the State to deliver health and social services directly, is in a position to provide itinerant and local services in an administratively efficient manner.

3. The North Slope Borough is currently working on setting up a day care center. This development is an opportunity to provide training and establish a "tradition" of service to handicapped children in the context of a community day care program.

4. The North Slope Borough's Interagency Coordinating Council forms a basis for planning and case management. Through the Council, service providers can develop meaningful strategies for working together and with service users to strengthen and expand the service delivery system.

5. The various communities on the North Slope, in conjunction with the North Slope Borough Health and Social Service Agency, could use the current lack of in-home support services in the region to develop an innovative program of national significance. The Inupiat Community of the Arctic Slope (ICAS) has received a federal developmental disabilities discretionary grant to hire and train people to provide support services. The time is right and the financial backing is available to create a pilot project for home and family support specialists.

6. Early Childhood Education programs are on-going in all villages on the Slope. This set-up provides the opportunity to expand services in Barrow to increase enrollment and to make special efforts to enroll handicapped students, making sure that no handicapped child is denied service.

7. The North Slope Borough has successful experience in employing, training, and supervising local personnel and implementing locally based programs such as community health aides. This experience provides a strong basis for initiating local support services such as homemakers, home health aides, family counseling and training through the employment of "parent aides" as proposed by ICAS.

8. The Indian Child Welfare Act (ICWA) has set in motion activities which encourage and facilitate local placement for foster care and adoption of dependent children. This service will impact handicapped children as increased attempts are made to insure that children are placed with families in their own culture and village.

9. The new receiving home in Barrow is a major initial resource which allows for local short-term out-of-home care. Its existence favors the reduction in rate of out-of-region residential placements. It also provides a setting for local screening, assessment and evaluation of children with special needs.

CHAPTER 6

THE NORTHWEST REGION

Demographics

The Setting

The Northwest Region contains about 67,000 square miles consisting of the valleys of the Noatak, Kobuk, and Selawik Rivers, the Seward Peninsula, and the drainages into Kotzebue Sound and a portion of Norton Sound. The region reaches as far south as St. Michael on the Yukon River; north to the western Brooks Range; and, west to the Arctic Ocean. (Arctic Environmental Information and Data Center, 1975a)

The Kotzebue Sound Subregion

The Kotzebue Sound subregion consists of the area encompassed by the NANA Native regional corporation, or the Kobuk census division. It contains eleven villages (twelve when Point Hope is included) along the northern edge of the Seward Peninsula, around Kotzebue Sound to the southern boundary of the North Slope Borough, and eastward beyond Kobuk. Altogether, the subregion contains over 41,000 square miles of very sparsely populated territory. Kotzebue is the largest settlement and the subregional center for the surrounding villages.

Transportation is mostly by air or water, with roads practically non-existent except for the gravel streets inside Kotzebue. As the regional center, Kotzebue has a modern airport capable of landing large jets. The other communities in the region have airstrips of varying descriptions. During the summer, there is ship access to the coast, and much inland travel is by small boat. In winter, intervillage travel is by snowmachine and dogsled. Kotzebue is linked by established air routes with all of the region's villages, Point Hope, Nome, Anchorage, and Fairbanks. Some of the villages are connected by air directly with each other; others require routing through Kotzebue. Major air carriers include Wien Air Alaska, Alaska Airlines, and Harold's Air Service, with bush flights linking Kotzebue with the villages.

The Norton Sound Subregion

The Norton Sound subregion consists of seventeen villages and towns along the western coast of Alaska and on the southern three-fourths of the Seward Peninsula. Nome is the largest community, serving as the regional center. The area, covering 24,968 square miles, extends from north of the Yukon River Delta along the coast to the western tip of the Seward Peninsula. It also includes St. Lawrence, Little Diomede, and King Islands.

As in the Kotzebue Sound area, transportation in the Norton Sound subregion is mostly by air or water. Nome and Unalakleet have airports capable of handling jet traffic; all of the smaller villages have gravel airstrips. Nome has scheduled air service to its surrounding communities, Kotzebue, Fairbanks, and Anchorage via Wien Air Alaska, Alaska Airlines, and Harold's Air Service. It also has several smaller flight services. There are approximately 350 miles of State secondary highways radiating out of Nome which are open only during the summer. In the winter, intervillage travel is by snowmachine or dogsled. (South Central Health Planning and Development, 1982)

The People

The population of the northwest region was 12,525 in 1981, with 4,960 in the Kotzebue Sound subregion and 7,565 in the Norton Sound subregion. (Alaska Department of Labor, 1982c) Inupiat people remain the majority of the population of the Kotzebue Sound subregion, making up about 85% of the total. In the Norton Sound subregion, the Inupiat live on the northern mainland, King Island, and Little Diomede Island. The Central Yupik inhabit the villages south of Unalakleet. On St. Lawrence Island, the population is Siberian Yupik, who are culturally and linguistically related to the Eskimos of the Chukotsk Peninsula of Russia. (South Central Health Planning and Development, 1982) The northwest region has a very large proportion of children among its population, especially in the Kotzebue Sound subregion, where over 48.5% are under 21. Overall, 46.7% of the residents of the northwest region are under age 21. Table 6-1 depicts the population of the northwest region by age and subregion. With an average annual growth from 1970 to 1981 of 2.53%, the northwest region is expected to grow to 13,476 people in 1984 and 14,743 by 1988, as shown in Table 6-2.

Tables 6-3 and 6-4 outline village-by-village populations for the two subregions of the northwest region, as of the 1980 census.

The Economy and Culture

Although western civilization over the past hundred years has changed the pattern of Eskimo life considerably, most Natives in the northwest region still remain economically and culturally oriented to the same subsistence resources that supplied their culture prior to contact. Except for Nome and a few mining camps, every settlement in the region is located according to the availability of game, fish, or fuel. The seasonal life patterns of most of the villages are still clearly influenced by the movement of fish, caribou, and marine mammals, and subsistence remains an integral part of the village economy. While new opportunities with Native corporations and other commercial enterprises have drawn a significant number of wage earners to Nome and Kotzebue, a substantial part of the money they earn is used to purchase durable goods related to the subsistence way of life -- outboard motors, snowmachines, guns, and other supplies. (Arctic Environmental Information and Data Center, 1975a; South Central Health Planning and Development, 1982)

At present, the cash income of the region is based on government spending (services, public assistance payments, and public works), tourism, mineral exploration, and the export of locally produced goods. Government is by far the most important source of income, and its role as the base of the regional economy is growing.

NORTHWEST REGION

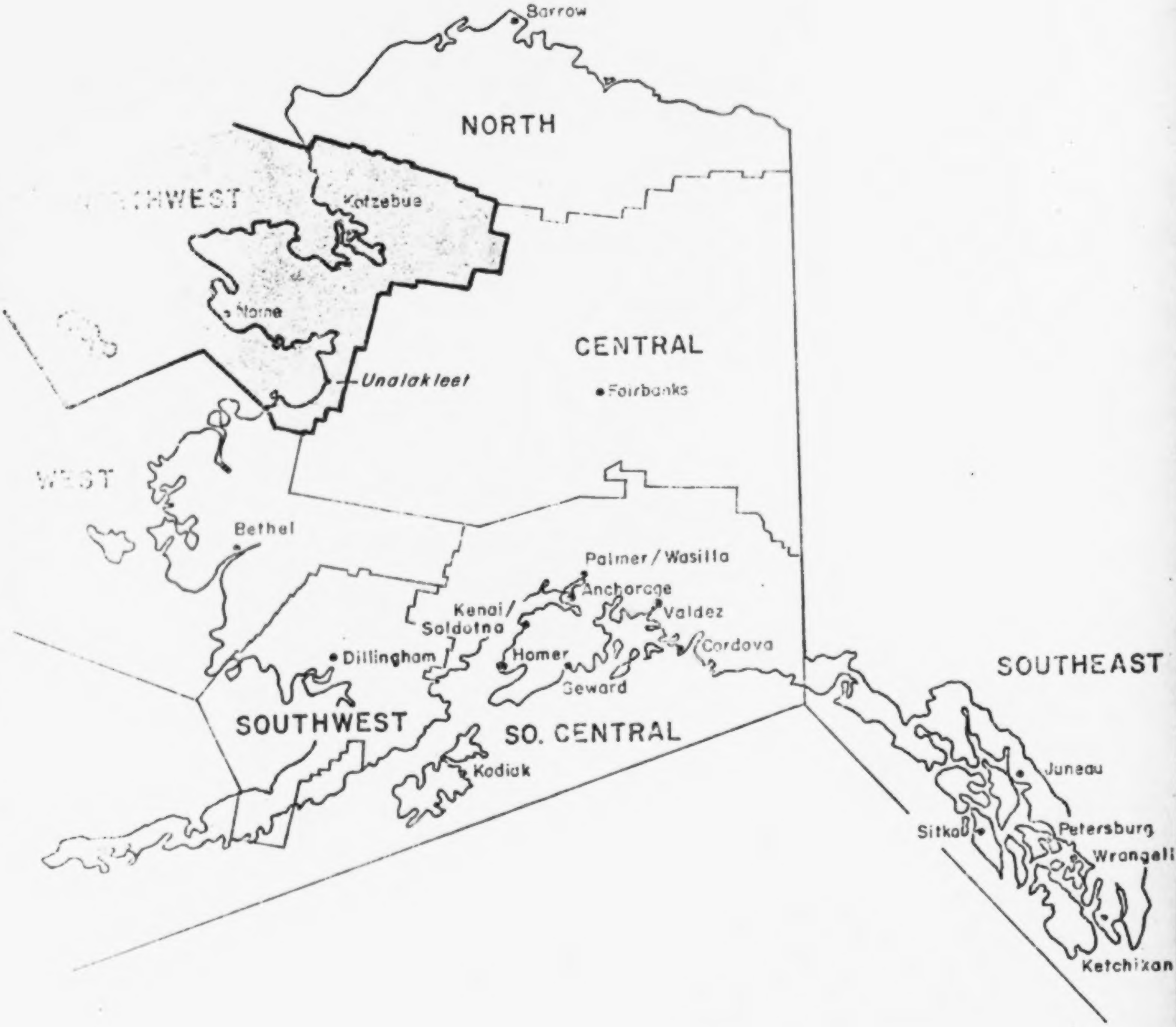
Barrow
NORTH
NORTHWEST
Kotzebue
Nome
Unalakleet
CENTRAL
Fairbanks
WEST
Bethel
Palmer / Wasilla
Anchorage
Valdez
Kenai/
Soldotna
Cordova
Homer
Dillingham
Seward
SOUTHEAST
SOUTHWEST
SO. CENTRAL
Kodiak
Juneau
Sitka
Petersburg
Wrangell
Ketchikan

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TABLE 6-1

POPULATION OF THE NORTHWEST REGION BY AGE AND SUBREGION, 1980

	Population by Age Group					
Subregion	0-2	3-5	6-20	21-64	65+	Total
Kotzebue Sound	365	313	1,667	2,237	249	4,831
Norton Sound	447	421	2,092	3,238	339	6,537
TOTAL	812	734	3,759	5,475	588	11,368

Source: U.S. Department of Commerce, Bureau of the Census. 1980 Census of Population, General Population Characteristics, Part 3 Alaska. PC80-1-B3 Alaska. Washington, D.C. August, 1982. Pp. 3-56 - 3-57.

TABLE 6-2

POPULATION OF THE NORTHWEST REGION BY AGE GROUP, 1980 and PROJECTED TO 1984 and 1988

Age Group	1980	1984	1988
0-2	812	962	1,053
3-5	734	871	952
6-20	3,759	4,457	4,876
21-64	5,475	6,490	7,100
65+	588	697	762
TOTAL	11,368	13,476	14,743

Source: U.S. Department of Commerce, Bureau of the Census. 1980 Census of Population, General Population Characteristics, Part 3 Alaska. PC80-1-B3 Alaska. Washington, D.C. August, 1982. Pp. 3-56 - 3-57.

TABLE 6-3

POPULATION OF THE KOTZEBUE SOUND SUBREGION BY VILLAGE, WITH COMMUNITY LEVELS, 1980

Village	Level of Community	Population
Ambler	I	192
Buckland	I	177
Deering	I	150
Kiana	I	345
Kivalina	I	241
Kobuk	I	62
Kotzebue	III	2,054
Noatak	I	273
Noorvik	I	492
Selawik	I	361
Shungnak	I	202
SUBREGIONAL TOTAL		4,831

Source: Alaska Department of Labor. Alaska Population Overview 1981. Juneau, Alaska. 1982. P. 16.

TABLE 6-4

POPULATIONS OF THE NORTON SOUND SUBREGION BY VILLAGE WITH COMMUNITY LEVELS, 1980

Village	Level of Community	Population
Brevig Mission	I	138
Diomede	I	139
Elim	I	211
Gambell	I	445
Golovin	I	87
Koyuk	I	188
Nome	III	2,301
Perkinsville	I	33
Fort Clarence	I	29
St. Michael	I	239
Savoonga	I	491
Shaktoolik	I	164
Shishmaref	I	394
Stebbins	I	331
Teller	I	212
Unalakleet	II	623
Wales	I	133
White Mountain	I	125
SUBREGIONAL TOTAL		6,537

Source: Alaska Department of Labor. Alaska Population Overview 1981. Juneau, Alaska. 1982. P. 16.

The level of economic activity in the region is low and is reflected in high unemployment rates and relatively low per capita incomes. With career development programs and efforts to send young people on to college, Natives are gaining in the employment realm. However, non-Natives are employed in year-round service, trade, or transportation industries or by government; many Natives are employed only seasonally. Important industries based on natural resources in the region are commercial fishing, reindeer husbandry, mining, trapping, arts and crafts, and tourism.

Government is the largest single employer and source of cash income in the region. Government construction activities are important sources of jobs during summers when village housing or other projects are underway. However, these projects cannot be counted on to provide steady, permanent employment. Residents are also employed on an emergency basis by the Bureau of Land Management to fight forest fires. Schools, post offices, public health services, health and welfare agencies, and local municipal administrations are some of the other government employers in the region.

Unlike the other communities in the northwest region, Nome was originally a "white man's town," having begun because of the goldrush. Eskimos moved into Nome, but the white man's values predominated and the Native way of life changed from a subsistence hunting and fishing economy to a money economy.

Over the past two years, the Kotzebue Sound subregion has experienced a resurgence of Inupiat culture and values. The movement has grown into the Inupiaq Ilitqusiat -- a belief in the Inupiat civilization as defined by the elders and a commitment to the Inupiat lifestyle. Through the Inupiaq Ilitqusiat movement, the Inupiat people of the NANA region are designing and launching their own programs to: 1) teach human (Inupiaq) values; 2) develop individual identity and self-esteem; 3) develop incentive and motivation; 4) develop use of the Inupiaq language; 5) preserve Inupiaq cultural heritage; and, 6) teach traditional skills.

Social Problems

As in other parts of rural Alaska, the northwest region's people are experiencing rapid change, the transition of lifestyles and economies. Resultant social problems include alcohol abuse, high suicide rates, domestic violence, child abuse and neglect, crime, and family disintegration. (Northern Alaska Health Resources Association, 1982; South Central Health Planning and Development, 1982)

The Target Population

As described in Chapter V, all children who are substantially handicapped are considered to be developmentally disabled. These people make up about 3% of the age groups 0-2 and 3-5 and 1.87% aged 6-20. Adults are counted among the developmentally disabled only if their impairments arose in childhood. On the average, 1.49% of the population aged 21-64 and .5% aged 65+ are developmentally disabled. In addition, about 1.90% of the people aged 21-64 and 10%

aged 65+ have other substantial limitations. (Northern Alaska Health Resources Association, 1983)

Table 6-5 summarizes the number of northwest region residents with substantial disabilities. Altogether, there were approximately 201 developmentally disabled and 163 otherwise disabled people in the northwest region in 1980. By 1988, those numbers are expected to rise to 262 and 211 respectively. Around 120 will be among the school-aged (3-20) population. Table 6-6 estimates the numbers of substantially disabled people by age group for each subregion for 1980 and projected to 1984 and 1988.

TABLE 6-5

NORTHWEST REGION ESTIMATED POPULATION OF PERSONS WITH SUBSTANTIAL HANDICAPS, 1980

	Persons with Substantial Handicaps		
Age Group	Developmentally Disabled	Other	Total
0-2	24	0	24
3-5	22	0	22
6-20	70	0	70
21-64	82	104	186
65+	3	59	62
TOTAL	201	163	364

Sources: U.S. Department of Commerce, Bureau of the Census. 1980 Census of Population, General Population Characteristics, Part 3 Alaska. PC80-1-B3 Alaska. Washington, D.C. August, 1982. Pp. 3-56 - 3-57.

Governor's Council for the Handicapped and Gifted. 1981-83 Alaska Developmental Disabilities State Plan. Fairbanks, Alaska. August, 1980. Pp. 25-29.

Urban Institute. Report of the Comprehensive Service Needs Study. DHEW-RSA. June, 1975. Pp. 57-58, 72.

Older Alaskans Commission. Phone interview with Lawry Robertson. January, 1983.

Methodology: See Table 6-6.

TABLE 6-6

NORTON SOUND SUBREGION
SUBSTANTIALLY DISABLED POPULATION
BY AGE, 1980 and PROJECTED TO 1984 and 1988

Age Group	Substantially Handicapped Population*		
	1980	1984	1988
0-2	13	17	19
3-5	13	16	16
6-20	39	49	54
21-64	110	138	153
65+	36	45	49
TOTAL	211	265	291

KOTZEBUE SOUND SUBREGION
SSUBSTANTIALLY DISABLED POPULATION
BY AGE, 1980 and PROJECTED TO 1984 and 1988

Age Group	Substantially Handicapped Population*		
	1980	1984	1988
0-2	11	12	13
3-5	9	10	11
6-20	31	34	37
21-64	76	82	89
65+	26	28	30
TOTAL	153	166	180

* Includes both developmentally disabled and other disabled people.

Methodology: Proportions of handicaps are calculated as follows:

1. Developmental disabilities
    - a. 3% of the population aged 0-2 and 3-5.
    - b. 1.87% of the population aged 6-20.
    - c. 1.49% of the population aged 21-64.
    - d. .5% of the population aged 65+.
2. Other disabilities
    - a. 1.90% of the population aged 21-64.
    - b. 10% of the population aged 65+.

Sources: See Table 6-5.

Community Descriptions

The Kotzebue Sound Subregion

The Kotzebue Sound subregion is comprised of eleven villages. Kotzebue, a Level III community, is the largest village, with 2,054 people in 1981. Kotzebue serves as the service and commercial center for all of the area encompassed by the NANA regional corporation and is a major transportation hub for the region. Approximately 72% of Kotzebue's population is Native; about 54% is male. (U.S. Department of Commerce, Bureau of the Census; Alaska Department of Labor, 1982c)

Kotzebue has changed considerably over the past few years. There have been numerous new housing units constructed, along with more stores and restaurants. Also, the growth of the Maniilaq Association, including direct contracting with the State for human services, has broadened job opportunities and local self-determination.

As the regional center for the NANA region, Kotzebue maintains a modern airport, which handles daily flights to Anchorage, Fairbanks, Nome, and many villages. Kotzebue is also headquarters for the Northwest Arctic School District; the Maniilaq Association; the NANA Native regional corporation; and, the Kotzebue Service Unit of the Indian Health Service.

Ten Level I villages look to Kotzebue for health and social services, transportation, education, and commercial goods. All of these villages orient to Kotzebue for primary hospital care and receive itinerant services from Kotzebue. Although part of the North Slope Borough, Point Hope also receives services through Kotzebue because of its geographic location.

The ten Level I villages are scattered along the Chukchi Sea and Kotzebue Sound from Kivalina in the north to Deering in the south. Five are strung along the Kobuk River, from Kobuk in the east to Noorvik near Selawik Lake. They range in size from 62 at Kobuk to 492 at Noorvik, and, with the exception of Ambler, are at least 95% Native in population. Ambler is 88% Native. Populations in 1980 for all the villages are given in Table 6-3.

Transportation to and from the villages is mostly by air, with commercial bush carriers flying to every village at least twice weekly. The coastal villages also receive supplies from the BIA-North Star III. Local and intervillage transportation occurs by small boats, dogsleds, and snowmachines; there are no roads connecting any villages. Communications in all villages except Kobuk are by phone and telegraph. Kobuk, like the other villages, has radio communications through the school and the community health aide.

The Norton Sound Subregion

The Norton Sound subregion is comprised of seventeen villages and towns. Nome, a Level III community, is the largest village, with 2,301 residents in 1980. A first class city, Nome serves as the service and commercial center for the entire Norton Sound subregion. (U.S. Department of Commerce, Bureau of the Census)

As the regional center, Nome maintains a modern airport, with daily flights to Anchorage, Fairbanks, Kotzebue, and many villages. Nome is the headquarters for the Bering Straits School District; Nome City Schools; the Norton Sound Health Corporation; the Bering Straits Native Corporation; and, Kawerak, Inc. Nome is also home to the Norton Sound Regional Hospital, which has fifteen acute care and six long-term care beds. (South Central Health Planning and Development, 1982)

Unalakleet, with 623 residents in 1980, is the second largest population center in the Norton Sound subregion. Unalakleet is located on Norton Sound between St. Michael and Shaktoolik, 150 miles southeast of Nome. As a Level II community, Unalakleet serves as a subregional center for health and social services. (South Central Health Planning and Development, 1982)

The other fifteen villages in the Norton Sound subregion are Level I communities. For the most part, they skirt the Seward Peninsula and Norton Sound, running from Shishmaref in the north to St. Michael in the south. Gambell and Savoonga are located on St. Lawrence Island, 200 and 165 miles from Nome respectively. Diomede, on Little Diomede Island, borders the International Date Line in the Bering Straits. Community sizes range from 29 at Fort Clarence to 491 at Savoonga. Populations in 1980 for all the villages are shown in Table 6-4.

Transportation is mostly by air or water, even though flying conditions are often poor. Communication in all but two villages is by telephone and radio.

The Norton Sound subregion has the second highest proportion of people living in poverty of all the regions in south central Alaska. Unemployment levels remain high, especially during the winter. (South Central Health Planning and Development, 1982)

Service Flow Patterns

Seen as a whole, the Northwest Region has two major service centers and one lesser center. Kotzebue is the hub of the NANA region, as Nome is for the Norton Sound subregion. The two areas are largely separate from each other for health services and, increasingly, for social services because of the regional health corporations. The Maniilaq Association, by contracting directly with the State to provide services previously delivered out of Nome, is gradually increasing this separation.

Unalakleet is a subregional center for the Norton Sound area, providing itinerant public health and other services to nearby communities.

For specialized care not available within the Northwest Region, most residents travel to Anchorage.

Available Services

Health Services

The Kotzebue Sound Subregion

The Maniilaq Association and the Indian Health Service are the major health care providers in the NANA region. The Maniilaq Association has grown dramatically in the past few years and has assumed a contract with the State to deliver the public assistance and social services programs directly. Altogether, the Maniilaq Association operates 34 programs, including: 1) community health practitioners; 2) accident and injury control; 3) public health nursing; 4) Women, Infants, and Children; 5) emergency medical services; 6) alcoholism treatment; 7) mental health; and, 8) women's shelter. All of these programs are headquartered in Kotzebue, but most offer itinerant services to the Level I communities in the subregion. The alcoholism program has substance abuse counselors stationed in each village.

The Community Health Practitioner program forms the heart of health services outside of Kotzebue. The ten village clinics, their staffs, and the support staff in Kotzebue are the primary source of health care for most of the subregion's people. Each village now has a well-equipped clinic, with new clinics completed in 1982 in Ambler, Buckland, Kobuk, and Shungnak and clinics under construction in Deering and Kivalina.

The Public Health Nursing program is a comprehensive service which tries to prevent illness through systematic and routine health care programs such as: immunizations; tuberculosis; sexually transmitted disease; family planning; maternal services; infant and preschool health services; school-aged children services; handicapped children's program; early and periodic screening, diagnosis, and treatment; and, adult health services. The public health nurses provide outpatient services in Kotzebue and itinerant services to all the villages.

The other major provider of health services in the subregion is the Indian Health Service, through the Kotzebue Public Health Service Hospital. This facility serves the Native and non-Native population of the NANA region. The hospital maintains 31 beds, including accommodations for obstetrics and alcohol detoxification. Other services offered are surgery, post-operative recovery, dentistry, and morgue. Residents of the area usually seek routine services at the Kotzebue facility. For illness or injuries requiring specialized services beyond those available locally, Native people frequently go to the Alaska Native Medical Center in Anchorage. Non-Native residents seek care in Fairbanks and Anchorage.

Besides the federal and State-funded services in the subregion, there is one dentist in private practice in Kotzebue.

Table 6-7 outlines the health services provided in the Kotzebue Sound subregion by village. Other than services rendered by the community health practitioners and village substance abuse counselors, all health care in the Level I communities is provided on an itinerant basis.

Norton Sound Subregion

Services in the Norton Sound subregion are very similar to those provided in the Kotzebue Sound subregion. The Norton Sound Health Corporation, based in Nome, oversees the community health aide program and the Norton Sound Regional Hospital. The State of Alaska provides public health nurses based in Nome and Unalakleet who itinerate to the villages.

All of the communities in the Norton Sound subregion, with the exception of Council, have community health aides, and most also have alternate health aides. All of them except Teller, Wales, and White Mountain receive itinerant public health nurse visits. All villages except Council, St. Michael, and Savoonga have free-standing health clinics. Mental health and alcoholism services are provided on an itinerant basis to Koyuk, St. Michael, Shaktoolik, and Stebbins.

The Norton Sound Regional Hospital, formerly a Public Health Service facility, has fifteen acute care and six long-term care beds. Basic services include primary acute care, outpatient services, obstetrics, and emergency care and stabilization. Patients requiring services beyond the capabilities of the local hospital are flown to Anchorage.

Table 6-7 outlines the health services provided within the Norton Sound subregion.

Support Services

Support services are those services which are needed in addition to adequate medical services, educational and vocational services, and employment opportunities in order for a substantially handicapped person to live independently or with his/her family. There are three major types of support services - maintenance services, living skills training services, and material support services. Table 6-8 summarizes the support services available in the Northwest Region.

Maintenance Services

Day care services are provided in the Northwest Region through a day care center in Kotzebue, day care homes, and informal sitter arrangements. The Alaska Department of Community and Regional Affairs operates the Day Care Assistance Program to help economically stressed families to offset the high cost of child care in some communities. This program is not a welfare program but rather is an economic/community development program that provides for a steady labor market for employers and allows parents to be steady and productive employees. The Day Care Assistance Program supplemented child care payments for a total of 154 families in Kotzebue, Nome, and Noorvik in FY 1983. The total budget for this program was $130,828, with an average cost per child of $850. Despite the availability of some day care services and the Day Care Assistance Program, there were no substantially handicapped children enrolled in these programs in FY 1983. Any "sitter" services which handicapped children used were obtained informally.

TABLE 6-7

NORTHWEST REGION
HEALTH SERVICES BY COMMUNITY, 1983

		Prevention					Early Identification											
Community	Level	PC	SHE	PA	WCP	I	PNT	MDS	VHS	MTS	D&E	MS	DS	OT	PT	SSH	HHN	HHA
Kotzebue Sound Subregion																		
Ambler	I	L	L		L	L		I	I			I	I			I		
Buckland	I	L	L		L	L		I	I			I	I			I		
Deering	I	L	L		L	L		I	I			I	I			I		
Kiana	I	L	L		L	L		I	I			I	I			I		
Kivalina	I	L	L		L	L		I	I			I	I			I		
Kobuk	I	L	L		L	L		I	I			I	I			I		
Kotzebue	III	L	L		L	L	L	L	L	L	L	L	L			L/I		
Noatak	I	L	L		L	L		I	I			I	I			I		
Noorvik	I	L	L		L	L		I	I			I	I			I		
Selawik	I	L	L		L	L		I	I			I	I			I		
Shungnak	I	L	L		L	L		I	I			I	I			I		
Norton Sound Subregion																		
Brevig Mission	I	L			L	L		L	I			I	I			I		
Diomede	I	L			L	L		I	I			I	I			I		
Elim	I	L			L	L		I	I			I	I			I		
Gambell	I	L			L	L		I	I			I	I			I		
Golovin	I	L			L	L		I	I			I	I			I		
Koyuk	I	L			L	L		I	I			I	I			I		
Nome	III	L			L	L	L	L	L	L	L	L	L			L		
Perkinsville	I																	
Fort Clarence	I																	
St. Michael	I	L			L	L		I	I			I	I			I		
Savoonga	I	L			L	L		I	I			I	I			I		
Shaktoolik	I	L			L	L		I	I			I	I			I		
Shishmaref	I	L			L	L		I	I			I	I			I		
Stebbins	I	L			L	L		I	I			I	I			I		
Teller	I	L			L	L												
Unalakleet	II	L			L	L		I	I			I	I			I		
Wales	I	L			L	L		I	I			I	I			I		
White Mountain	I	L			L	L												

I = itinerant L = locally-based

PC = Prenatal care
SHE = School health education
PA = Public awareness
WCP = Well-child program
I = Immunizations
PNT = Prenatal Testing

MDS = Medical/developmental screening
VHS = Vision and hearing screening
MTS = Metabolic screening
D&E = Diagnosis and evaluation of handicapping conditions
MS = Medical services

DS = Dental services
OT = Occupational therapy
PT = Physical therapy
SSH = Speech and hearing services
HHN = Home health nursing
HHA = Home health aide services

Sources: Northern Alaska Health Resources Association. Health Resource Development Plan for Northern Alaska, 1982. Fairbanks, Alaska. April, 1982.
South Central Health Planning and Development. Health Systems Plan 1982-86. Anchorage, Alaska. 1982.
Maniilaq Association. Maniilaq Association 1982 Annual Report. Kotzebue, Alaska. 1982.

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Twenty families in the Northwest Region are estimated to need sitter/respite services for their substantially disabled members. At this time, these services are unavailable. Personal aide and attendant services, which provide intensive and individualized in-home personal care for persons who are substantially disabled and who, without such intensive assistance, would be unable to live in their own homes, are also not available in the Northwest Region.

Homemaker services provide household assistance, chore service, and/or non-medical personal assistance to enable a person and his/her family to live at home. The Alaska Division of Family and Youth Services contracts with Alaska Management Technologies to provide homemaker services statewide. However, services are currently not offered in many communities. In the Norton Sound subregion, Nome, Gambell, Brevig Mission, Savoonga, Teller, Shishmaref, Golovin, Wales, and Shaktoolik all have trained homemakers and were served during FY 1983. However, Unalakleet, a Level II community, lacked service. Sixteen substantially handicapped people received homemaker service at a total cost of $15,136. Each person received an average of 77.5 hours of service at a mean cost per person of $946. The total cost of homemaker services in the Norton Sound subregion, for handicapped as well as non-handicapped individuals, was $104,007 in FY 1983. In the Kotzebue Sound subregion, the Maniilaq Association provided homemaker services on contract with the State. In FY 1982, 21 people were served in the communities of Ambler, Buckland, Kiana, Selawik, and Shungnak. The proportion of these clients who were substantially handicapped is unknown.

Home health aide support is a special resource made available to individuals who need health-related personal care in order to maintain an independent, community-based living arrangement. Home health aide services were provided to two clients in Nome through the Alaska Division of Public Health in FY 1983. The cost per client was $1,886, for a total of $3,772. No other communities in the Northwest Region has home health aide, home nursing, or personal aide/attendant services.

Specialized transportation services for the handicapped are not available in the Northwest Region except as provided through the school districts and senior citizens programs. Special Olympics is the only recreation program for handicapped individuals outside of school-based activities.

Developmental Services

There are no developmental services available in the Northwest Region other than activities through the school districts' special education programs. Some training takes place informally through the community health aides, itinerant public health nurses, homemakers, and others.

TABLE 6-8

SUPPORT SERVICES AVAILABLE IN THE NORTHWEST REGION, FY 1983

Type of Service	Availability*	Substantially Handicapped Clients Served	Average Cost Per Client	Total Costs for Handicapped Clients
MAINTENANCE SERVICES				
Day care/sitter	P	NR	NR	NR
Day care assistance program	P	0	$850	0
Respite/specialized sitter	I	NR	NR	NR
Homemaker	P	16**	$946**	$15,136
Home health aide	P	NR	$1,886	NR
Home health nursing	U	--	--	--
Personal aides and attendants	U	--	--	--
Transportation	S	NR	NR	NR
Recreation	S/I	NR	NR	NR
LIVING SKILLS TRAINING SERVICES	S/I	NR	NR	NR
MATERIAL SUPPORT				
Financial assistance	A	NR	NR	NR
Environmental adaptive equipment	U	--	--	--
Personal adaptive equipment	U	--	--	--

* A = available; P = available in only some parts of the region; U = unavailable; S = through the schools.
** = Not including services provided by the Maniilaq Association.

Sources: Alaska Department of Community and Regional Affairs, Division of Employment Opportunity. Day Care Assistance Programs Mid Year Summary, FY 1983. Juneau, Alaska. February, 1983.
Alaska Department of Community and Regional Affairs, Division of Employment Opportunity. Unpublished data concerning the day care assistance grant program, FY 1983. Juneau, Alaska. March, 1983.
Alaska Department of Health and Social Services, Division of Family and Youth Services. Computer print-out on homemaker services program utilization. Juneau, Alaska. December, 1982.
Alaska Department of Health and Social Services, Division of Public Health, Section of Nursing. Home Health Aide Services, FY 1983. Juneau, Alaska. May 17, 1983.
Alaska Management Technologies. Correspondence with the Governor's Council for the Handicapped and Gifted concerning homemaker services program utilization. Juneau, Alaska. January, 1983.
Maniilaq Association. Maniilaq Association 1982 Annual Report. Kotzebue, Alaska. 1982.

Material Support Services

Cash assistance is available to eligible individuals and families in the Northwest Region on the same basis as elsewhere in the state. The major categories of special assistance to the handicapped are Aid to the Disabled and Aid to the Blind, through the Alaska Division of Public Assistance, and Supplemental Security Income (SSI) payments, in accordance with the federal Social Security Act.

Personal adaptive equipment is provided to disabled children through Alaska's Handicapped Children's Program. Personal adaptive equipment for adults and environmental adaptive equipment for people of all ages are generally unavailable except through private or third-party payment or on an informal basis.

Residential Services

Services Available in the Northwest Region

Over 95% of the developmentally disabled people from the Northwest Region live in their own homes in the natural environment. For children, living in the natural environment includes residing with parents or other relatives. It may include foster care and adoption placements.

The Alaska Division of Family and Youth Services provides foster care for two handicapped youth aged 6-20 in the Northwest Region. These services are general foster care placements and are the same as foster care offered to non-handicapped children. Therefore, these children are considered to be living in natural environments, except for the financial subsidy provided for their support.

The Alaska Division of Family and Youth Services also offers subsidized adoptions to enable adoptive placement of children who require medical services beyond the financial abilities of their adoptive families. During FY 1983, there was one child in the Northwest Region who was in a subsidized adoptive placement.

There are no other augmented or devised residential environments such as specialized foster care, semi-independent apartments, or group homes for handicapped individuals located in the Northwest Region. Although handicapped individuals may receive services at the Maniilaq Association's youth group home, the Nome Receiving Home, the women's shelters, or the two hospitals in the area, these are generic services which are available to the general population during a time of special need. There are no local programs designed for the special residential needs of disabled people. One developmentally disabled person was served by the Nome Receiving Home during FY 1983.

No persons from outside of the Northwest Region received residential care within the region.

Out-of-Region Facilities Utilized by Residents of the Northwest Region

During FY 1983 sixteen people from the Northwest Region received residential care outside of their home communities. Nine of these people were in protective environments, with one at Wesleyan Nursing Home in Seward, seven at the Harborview Developmental Center in Valdez, and one in the Hope Cottages ICF-MR facility in Anchorage.

During this time period, three individuals were in devised environments. One child of school age was in the Hope Cottages Children's Group Home program in Anchorage. Of the two adults, one was in a Hope Cottages Adult Group Home and one was in a Fairbanks Rehabilitation Association Group Home.

Four individuals were placed in augmented environments outside of the Northwest Region. One adult and one child were placed in the ARMSI-Satellite Home Program in Anchorage. Two adults were in Fairbanks Rehabilitation Association programs; one in the apartment program and one in the specialized foster care program.

Table 6-9 summarizes residential placements of Northwest Region residents during FY 1983.

Residential Service Needs of Northwest Region Residents

Because of the small population size of the Northwest Region, there can be considerable random variation in service needs. This fluctuation sometimes results in projections of need which are lower than the numbers of people receiving service. In these cases, it is impossible to tell without individual functional assessments whether persons are inappropriately placed or whether they are in fact well placed but were simply uncounted by the prediction method. The surveys which have been undertaken for Alaskan residents, indicate that there has been a tendency to place disabled persons in higher more protective levels of care than their conditions might warrant.

In the Northwest Region, as Table 6-10 shows, an estimated thirteen individuals need some sort of residential assistance, with five needing augmented environments, four devised, and four protective. However, nineteen people are receiving residential services. At the same time, there are three children aged 0-5 who need services but who are receiving none.

Cost of Residential Services Provided in the Northwest Region

The only residential services routinely provided within the Northwest Region are those for natural augmented environments, in this case subsidized adoption and foster care. In FY 1983, $3,600 from the State General Fund was allocated for subsidized adoption, at an average daily cost of $9.86 per recipient. During the same time period, $26,441 from the State General Fund was budgeted for foster care, at an average daily cost of $18.11 per recipient. When the two programs are combined, total expenditures were $30,041, at an average daily cost per individual of $13.99.

One handicapped individual was cared for at the Nome Receiving Home. The average daily cost of care in that devised environment was $116.97, which would equal $42,694 for the full year.

Costs for residential services in the Northwest Region are summarized in Table 6-11.

Educational Services

Infant Learning Program

Infant Learning Program (ILP) services began in the Northwest Region in 1981 following program planning by the Bering Strait Human Services Council. Grant funds of $90,000 were received from the Division of Public Health to begin serving newborn babies and young children under age 3 in Nome and the surrounding 16 area villages.

The Human Service Council, formed in 1980 to bring together agencies concerned with exceptional children and direct care agencies specializing in physical and mental health, social and educational services. The Council itself serves as a direct service planning and delivery team as well as the sponsoring agency for ILP services. At the end of the FY 83 program year, the Bering Strait Infant Learning Program had fifteen children enrolled: Nome, 7; Stebbins, 2; Shishmaref, 1; St. Michaels, 1; Brevig Mission, 2; and, Savoonga, 2.

During the past year, nine other children were enrolled and have since left the program: two moved away; three reached age 3; four had their problems ameliorated; and, four parents no longer wanted them enrolled.

TABLE 6-9

RESIDENTIAL PLACEMENTS OF NORTHWEST REGION RESIDENTS WITH SUBSTANTIAL HANDICAPS, FY 1983

Program by Type of Environment	Location	Number of Residents by Age Group				
		0-5	6-20	21-64	65+	Total
AUGMENTED						
ARMSI Satellite Home Program	Anchorage	0	1	1	0	2
FRA Specialized Foster Care	Fairbanks	0	0	1	0	1
FRA Apartment Program	Fairbanks	0	0	1	0	1
DFYS Subsidized Adoption	NW Region	0	1	0	0	1
DFYS Foster Care	NW Region	0	2	0	0	2
DEVISED						
Hope Cottages Children's Group Homes	Anchorage	0	1	0	0	1
Hope Cottages Adult Group Homes	Anchorage	0	0	1	0	1
FRA Group Homes	Fairbanks	0	0	1	0	1
PROTECTIVE						
Harborview Developmental Center	Valdez	0	0	7	0	7
Hope Cottages ICF-MR	Anchorage	0	1	0	0	1
Wesleyan Nursing Home	Seward	0	0	1	0	1
TOTAL		0	6	13	0	19

Source: Governor's Council for the Handicapped and Gifted. Survey of Provider Agencies, FY 1983. Fairbanks, Alaska. July, 1983.

TABLE 6-10

NUMBERS OF SUBSTANTIALLY HANDICAPPED PERSONS NEEDING AND RECEIVING RESIDENTIAL PLACEMENTS, NORTHWEST REGION, 1983

	Number of People				
Placement by Age Group	Needing Service	Receiving Service in Home Region	Receiving Service Outside Home Region	Unserved	Unserved in Home Region
AUGMENTED ENVIRONMENT					
0-5	1	0	0	1	1
6-20	1	3*	1*	0	0
21+	3	0	3	0	3
All ages	5	3*	4	1	4
DEVISED ENVIRONMENT					
0-5	1	0	0	1	1
6-20	1	0	1	0	1
21+	2	0	2	0	2
All ages	4	0	3	1	3
PROTECTIVE ENVIRONMENT					
0-5	1	0	0	1	1
6-20	1	0	1	0	1
21+	2	0	8**	[6]	2
All ages	4	0	9**	1[5]	4
TOTAL	13	3*	16*,**	[3]	11

* It would appear that four people aged 6-20 are receiving augmented living services, whereas only one should need this arrangement. The discrepancy may be due to random error in the prediction method. Discrepancies often occur when prevalence rates are applied to small populations. Variances are evidenced when cultural, socio-economic, health, accessibility, and other factors which are different from place to place come into play. Higher disability prevalence rates are suspected among Alaskan Natives because of health factors.

** There are more than six people aged 21+ placed in protective environments than should be the case based on projected needs. Some of these people might more appropriately be placed in natural, augmented, or devised environments. On the other hand, the discrepancy may be due to random error in the prediction method.

[] People "over-served" in protective settings who may be inappropriately placed.

Source: Governor's Council for the Handicapped and Gifted, FY 81-82 DD State Plan, Fairbanks, Alaska. Chapter 6.
Surveys of provider agencies. January, 1983.
Analysis of special education and residential placement data. June, 1983.

Methodology: Estimates of place of residence for substantially handicapped people are: 95% natural, 2% augmented, 1.7% devised, and 1.3% protective.

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TABLE 6-11

COSTS AND FUNDING SOURCES FOR RESIDENTIAL SERVICES PROVIDED IN THE NORTHWEST REGION, FY 1983

Facility/Program	Funding Source	FY 1983 Allocation for Services to Persons with Substantial Handicaps	Average Daily Cost Per Handicapped Resident
AUGMENTED			
DFYS Foster Care	State General Fund	$26,441	$18.11
DFYS Subsidized Adoptions	State General Fund	3,600	9.86
AUGMENTED, SUBTOTAL	All Sources	$30,041	$27.97
DEVISED			
Nome Receiving Home	State General Fund	42,694	116.97
GRAND TOTAL, ALL SETTINGS		$72,735	$144.94

Sources: Governor's Council for the Handicapped and Gifted. Survey of Provider Agencies, January - June, 1983. Fairbanks, Alaska. July, 1983.
Alaska Department of Health and Social Services, Division of Public Assistance. Monthly Nursing Home Census and Per Diem Rates. Juneau, Alaska. 1983.

Referrals were on file from Koyuk (1), Golovin (1), Unalakleet (2), and Gambell (2). Ten villages were unserved due to lack of staff and funding.

The stated objectives of the Nome-based program are:

> "Maximizing individual potential while minimizing institutionalization."
>
> "Strengthening the family unit and encouraging an attitude that parents are responsible for their child's learning process and can be successful in meeting that responsibility."
>
> "Involving local ILP aides who are hired and trained to implement each child's individual program so that parents deliver services daily, aides visit the homes weekly and the teacher visits monthly in each of the villages (except in Nome where the teacher visits homes weekly)." (Bering Strait ILP Grant Proposal for F84, February, 1983)

Following two years of efforts the Northwest Arctic School District will begin to provide similar home-based infant learning services in the late summer of 1983. Both Kotzebue and Norton Sound area villages will be served.

The Northwest Arctic program will be somewhat different from other ILPs. School special education personnel who are already assigned to particular villages for itinerant special education services will also provide ILP services to children and families. The program will be home-based but will utilize a variety of specialists and resource teachers to plan and deliver individualized services. The director of special education for the school district will oversee the program. Fifteen children are expected to be served, with many more screened for delays and provided other medical or health services as a result of early identification efforts.

Pre-Schools

Children from three to five years old receive early education services through several programs in the Northwest Region.

There are Head Start programs at Gambell (17), Savoonga (13) on St. Lawrence Island, Stebbins (18), and Unalakleet (26), all in the Norton Sound subregion. Kawerak serves 45 children at two sites in the Kotzebue subregion. Of the total 119 children in Head Start, 12 are handicapped and classified as speech-language impaired. No severely handicapped or developmentally disabled children are currently served. The three school districts in the area, Northwest Arctic, Bering Straits, and Nome, are required to provide special education services to certified handicapped or developmentally disabled children aged three and older. Northwest Arctic reports 15 children served with 1 teacher and 1 aide, Bering Straits served 11 with two aides: Nome data are not reported.

TABLE 6-12

NORTHWEST REGION
INFANT LEARNING PROGRAM ENROLLMENT STATISTICS, FY 1982

		Total Pop. 0-2	Disabled Children					ILP Utilization			Funding (in thousands)		
Community	Agency	FY80	At Risk	DD	Screened Svd	Enrolled	T	MDE	Contact Hours	Number Home Visits	FY82	FY83	FY84
Kotzebue	Northwest Arctic Schools	365	18	11	0	0	0	0	0	0	0	0	150.4*
Nome	Bering Strait Human Services	447	22	13	28	16	0	10	334	174	93.8	94.0	177.0
TOTAL		812	40	24	28	16	0	10	334	174	93.8	94.0	327.4

DD = developmentally delayed T = terminated MDE = received multi-disciplinary evaluations

* = FY84 funding includes $110,000 in a larger designated grant from the State to the NW Arctic plus a $40,400 grant from the Division of Public Health ILP budget. It appears that the $110,000 may not be available because of appropriation vetoes.

Sources: Division of Public Health, Infant Learning Program Year-End Report, F82, Anchorage. September, 1982.
Division of Public Health, FY84 budget allocations, Infant Learning Program Coordinator, Anchorage. August, 1983.

BIA, which operates schools at Diomede, Elim, Savoonga, and Shaktoolik, reports no children served and no funding for pre-school services for exceptional children.

Survey respondents indicated that pre-school programs are funded by four different agencies. Some villages have no pre-school opportunities. Coordination is difficult, funding limited, and resources insufficient to support strong child-find and program development activities for this age group.

With an age group population of 871 children, a three-to-five percent estimated need would indicate that 26-43 handicapped children may need pre-school services. Opportunities for educational services early in life are likely to reduce or prevent learning difficulties later.

Special Education K-12

The Nome City School District, with a total 1982-83 enrollment of 734 students, served 84 students, or 11%, in special education. Table 6-13 shows distribution across exceptionality categories. Three students were served out of district--2 at Anchorage's multihandicapped program and 1 at McLaughlin Youth Center. Outreach services from ARMSI were used for visually impaired and orthopedically handicapped students. Psychological and speech therapy services were obtained from private consultants, one from Anchorage and one from Nome.

Bering Strait REAA had a total of 927 students in fourteen schools. Its 146 special education students comprise 16% of the total enrollment.

Itinerant services are provided in the small schools with eight to thirty students; outreach services from Alaska Resources (ARMSI) help the district to provide services to students locally and to reduce out-of-district placements. No students were placed out of district in 1982-83.

Northwest Arctic REAA had a total enrollment of 1,496 students in twenty different schools. Of the 249 special education students, 71% were classified as speech impaired or learning disabled. Sixteen mentally retarded students were in school and one or two students were identified in each of the other exceptionality categories. Five students were served out of the region in Anchorage at API, McLaughlin, the Multihandicapped program or the State School for the Deaf.

BIA's five schools in the Northwest Region have a combined total enrollment of 210, with 31, or 15%, in special education programs. Schools at Diomede, Elim, and Shaktoolik have 33, 39, and 34 students respectively. Savoonga's enrollment is 104.

All Northwest Region students with handicaps who are served locally receive services part-day in regular classrooms and part-day in resource rooms. None spend the entire day in resource rooms or in settings isolated from non-handicapped students. Of the total 510 special education students in grades K-12, nine are served in six separate, specialized programs in Anchorage.

TABLE 6-13

1982-83 SPECIAL EDUCATION ENROLLMENT INFORMATION
NORTHWEST REGION

School District	Number of Schools	Total Enroll-ment	Number of Sp Ed Students	% of Total Enroll-ment	Exceptionality											
					MR	HH	D	SI	VH	SED	OI	OHI	SLD	DB	MH	Out of District
LEAs																
Nome	2	734	84	11	5	4		16	1	2	1		55			#
REAAs																
Bering Straits	14	927	146	16	12	2	1	15	1	3	1	1	107		3	
NW Arctic	20	1,496	249	17	16	2	1	60	1	1	2	2	162		2	5
BIAs																
Diomede		33	9	27									9			
Elim		39	4	10				1					3			
Savoonga		104	16	15	3			1					12			
Shaktoolik		34	2	2									2			
TOTALS		3,367	510**	15	36	8	2	93	3	6	4	3	350	0	5	9

** Does not include out-of-district

MR = Mentally Retarded, Etc.
HH = Hard of Hearing
D = Deaf
SI = Speech Impaired
VH = Visually Handicapped
SED = Seriously Emotionally Disturbed
OI = Orthopedically Impaired
OHI = Other Health Impaired
SLD = Specific Learning Disability
DB = Deaf/Blind
MH = Multiply Handicapped

Sources: Alaska Department of Education. 1982-83 School Year, P.L. 94-142 Count. Juneau, Alaska. December, 1982.
Alaska Department of Education. 1982-83 School Year, P.L. 89-313 Count. Juneau, Alaska. October, 1982.
U.S. Department of the Interior, Bureau of Indian Affairs, Anchorage Office. Data Search. Anchorage, Alaska. May, 1983.

TABLE 6-14

NORTHWEST REGION
1982-83 SCHOOL YEAR OUT-OF-DISTRICT PLACEMENTS

	Level of Home Comm.				Age Range				Exceptionality						Total Placements
Program Placement	I	II	III	IV	3-5	6-12	13-15	16-21	MR	D	SED	OI	SLD	MH	
Anchorage Mental Health Program			2			1	1							2	2
McLaughlin			1					1					1		1
Anchorage Mental Health Program	1		1			2								2	2
State School for the Deaf			1			1				1					1
API			1					1			1				1
McLaughlin	2							2					2		2
TOTALS	3		6			4	1	4		1	1		3	4	9

MR = Mentally Retarded
OI = Orthopedically Impaired
D = Deaf
SLD = Specific Learning Disability
SED = Seriously Emotionally Disturbed
MH = Multiply Handicapped

Sources: Alaska Department of Education, Office for Exceptional Children. Juneau, Alaska. March 1983.
Program Surveys, Governor's Council for the Handicapped and Gifted. Fairbanks, Alaska. June, 1983.

TABLE 6-15

1982-83 SCHOOL YEAR FUNDING FOR SPECIAL EDUCATION PUBLIC SCHOOLS NORTHWEST REGION

			F83 Funding Sources			
	Foundation Funding					
School District	Reg. Ed. Allotment	Special Ed. Allotment	Total	P.L. 94-142 Funding	P.L. 89-313 Funding	Total Funding
LEAs						
Nome	506,238	526,376	1,032,614	14,410		1,047,024
REAAs						
Bering Straits	1,733,944	855,361	2,589,305		101,178	2,690,483
NW Arctic	2,190,131	1,447,534	3,637,665		172,557	3,810,222
TOTAL	4,430,313	2,829,271	7,259,584	14,410	273,735	7,547,729

Sources: Alaska Department of Education, Division of Education Program Support. FY83 P.L. 94-142 and P.L. 89-313 Distribution Calculations, unpublished data. Juneau, Alaska. January, 1983.
Alaska Department of Education, Division of Management, Law, and Finance. Public School Foundation Program Calculations. Juneau, Alaska. March 2, 1983.

TABLE 6-16

1982-83 SCHOOL YEAR FUNDING FOR SPECIAL EDUCATION PUBLIC SCHOOLS AND BIA SCHOOLS NORTHWEST REGION

	FY83 Funding Sources					
	Funding					
Schools	3017 Funds	3101 Funds	Total	P.L. 94-142 Funding	P.L. 89-313 Funding	Total Funding
BIA						
Diomede	31,021	18,703	49,724			
Elim	10,540	3,741	14,281			
Sanoonga	35,302	16,209	51,511			
Shaktoolik	0	3,741	3,741			
TOTAL BIA SCHOOLS	76,863	42,394	119,257			119,257
	Reg. Ed.	Special Ed.	Total			
Total LEAs	506,238	526,376	1,032,614	14,410		1,047,024
Total REAAs	3,924,075	2,302,895	6,226,970		273,735	6,500,705
TOTAL PUBLIC SCHOOLS	4,430,313	2,829,271	7,259,584	14,410	273,735	7,547,729
TOTAL PUBLIC AND BIA SCHOOLS	4,507,176	2,871,665	7,378,841	14,410	273,735	7,666,986

Sources: U.S. Department of the Interior, Bureau of Indian Affairs, Anchorage Office. Data Run. Anchorage, Alaska. June 1, 1983.

Vocational Services

"Vocational services" is the term applied to the activities which assist a person in preparing for, securing, and maintaining employment. Some of the services are geared to school-aged children; others are more appropriate for adults. People with substantial handicaps need the same basic set of career and employment-oriented services as does the general population. The focus and intensity of services provided to people with substantial handicaps may be a bit different from those provided to the general population, but the goal of using these services remains the same - employment.

Division of Vocational Rehabilitation

The Alaska Division of Vocational Rehabilitation (DVR) is the major vocational agency of State government. DVR is charged under P.L. 93-112 and A.S. 23.15.010 with providing a full range of vocational evaluation, counseling, training, job placement, and follow-along services. Northwest Region residents receive DVR services within their area only through itinerant services to Nome and Kotzebue. For vocational evaluation, training, or placement in sheltered settings, Northwest Region residents must travel to other parts of the state.

School Districts

The school districts in the Northwest Region provide career and vocational education, pre-vocational training, and vocational training as components of the regular school curriculum. The Bering Straits School District offered 35 approved courses during the 1982-83 school year, including such things as auto mechanics, three-wheeler repair, wood shop, and custodial maintenance. Nome City Schools offered 33 courses, ranging from basic computers to dogsled construction. The Northwest Arctic School District had 84 courses, including hunting/trapping, reindeer management, and Native crafts, as well as typing, drafting, home nursing, and others. These services and courses are provided to all interested students and are not designed especially for the substantially handicapped.

Enabling Services

Case Management Services

Informally, case management functions are carried out by particular agencies currently providing services to a disabled person and his or her family. For families receiving health care, the community health aide and public health nurse are looked to for guidance, information, and advice by the families and other agencies. They may also assist, with family approval, in making referrals, planning, and obtaining, other needed services. Division of Family and Youth Services Social Workers also assist in case management as part of their provision of protective or other family services.

There is no formal case management "system" for people with disabilities, just as there is no such system for the general population or for other population sub-groups. For most services to be provided, however, there are requirements for individual case service planning, development of habilitation, rehabilitation, special education, or family service plans, which is the primary responsibility of the providing agency in consultation and coordination with other related service or health personnel.

Guardianship Services

Guardianship and conservatorship services for people who are disabled can only be provided for legally after following a process of filing a petition and having a hearing in Superior Court. Since guardianship, responsibility for the person and decisions for the person, and conservatorship, management of the person's finances, mean that some or all of the disabled or incapacitated person's legal rights are taken away, special legal proceedings must take place to make sure that rights are not taken away without due process and without basis.

The Second Judicial District includes the Northwest Region. Superior Court judges are at Nome and Kotzebue and petitions may be filed and heard there. State law provides that a visitor must be appointed to investigate the situation of the person for whom a guardian is sought, to see if guardianship is necessary to protect the individual, and to identify people who might serve as guardian. If the Court determines that guardianship is necessary and that there is no relative or friend to be guardian, the Court can assign the Public Guardian to handle the person's affairs.

Staff Training and Manpower Development Services

Each agency has responsibility to provide for staff training. P.L. 94-142 requires training of teachers and other special education personnel. Title VI-B funds are provided to the school district based on special education enrollment and are utilized for training as well as child find activities. The special education outreach program, ARMSI, provides training to local people on an itinerant basis. The Division of Family and Youth Services has a training center in Anchorage for social workers employed by the Division. The Division of Public Health provides health education and training and sets aside money for annual training of infant learning program teachers. Maniilaq, Kawerak, and the school districts in the region provide regular training for personnel.

Information and Referral

In the Northwest Region information about services and referral to services takes place informally and formally. Because of the small number of people living in villages and in Nome and Kotzebue word gets around fast about new services, new workers, and about people's impressions and perceptions of service delivery. Each service provider has a portion of the over-all responsibility to explain services, answer questions, make referrals, and coordinate with other workers and people in the community. A great deal of coordination is required because of the use of itinerant services. This means that local people must plan and coordinate schedules, trips, flights, and meetings between people in the villages such as the health aides as well as with itinerant providers who may be coming from Fairbanks, Anchorage, or beyond.

At this point in time there is no over-all coordination of health and social services information and referral.

Protection and Advocacy Services

Protective services are provided by the Division of Family and Youth Services. Legal services are available on a resident basis in Nome and Kotzebue and on an itinerant basis to the villages by Alaska Legal Services Corporation. Private attorneys practice in the region and private attorney services can be obtained from Fairbanks and Anchorage. The state Ombudsman in Fairbanks accepts and investigates complaints about state agencies and can travel to Nome and Kotzebue to investigate cases.

The only agency providing specialized protection and advocacy services to remedy violations of rights or due process, and to seek redress through negotiation, administrative, and legal means, and to provide assistance to disabled individuals who cannot access services themselves, is Protection and Advocacy for the Developmentally Disabled (P.A.D.D.). An advocate in Fairbanks can receive inquiries and provide services to the Northwest Region on an itinerant basis.

Obstacles and Opportunities

Obstacles

Every region has characteristics of geography, economics, population size, attitudes, and values which can present challenges in human service delivery. Many of these obstacles are similar from area to area; others are unique to particular regions or villages. Almost every problem can be overcome through dedication and creativity on the part of community residents. The following obstacles to service delivery for the handicapped have been identified in the Northwest Region:

1. The physical environment poses awesome challenges to regionwide service systems. The wide dispersal of people, long distances, and difficult travel conditions make it important to develop support competencies at the local level.

2. The small population size of the Northwest Region, particularly outside of Kotzebue and Nome, causes the provision of certain kinds of services not to be feasible. There are not enough clients to share overhead costs, nor can providers maintain their technical skills with so few people to serve.

3. The fact that the Maniilaq Association provides health and social services in the Kotzebue Sound subregion while the Norton Sound Health Corporation does do in its subregion hinders unified service delivery. There is no centralized plan for regional service development.

4. Lack of services in the past contributed to inappropriate placements of some clients and no services for others. There are now people in residential placements outside of their home communities who could be returned if adequate support services were available. Community services are needed, especially support services and placements in augmented environments.

5. Community residents have attitudes in some cases which work against the development of local, community placements for severely disabled people. Positive attitudes and awareness of what can be accomplished locally must precede community acceptance of and action.

6. A major concern in the rural areas of northwest Alaska is the lack of parents' understanding of their children's individual handicapping conditions and special needs and awareness of their rights and responsibilities in obtaining services for their children. A parent in a rural community who has just given birth to a special needs child is often without resources until that child reaches school age. Often, if a child is developmentally delayed due to lack of stimulation, an early program can ameliorate the problem. A child with a known handicap, placed in an early education/therapy program, may not require the extra care later in life that an unserved child with the same problem would. Parental awareness of services available to them and their children must be heightened to improve the prognosis of disabled infants and pre-schoolers.

7. Pre-school programs in the region are fragmented, with different services operated through the school districts, Kawerak, BIA, and the Head Start program. Some villages still have no pre-school opportunities. Coordination is difficult, funding limited, and resources insufficient to support strong child-find and program activities for the 3-5 age group.

Opportunities

The planning process enables communities to change obstacles into opportunities. Concerned service providers, clients, family members, and other interested people can work together to solve problems and implement community change.

Several opportunities in the area of services for the handicapped are now available in the Northwest Region:

1. State law requires the State to plan, develop, and implement a comprehensive system of services and facilities for the handicapped (A.S. 47.80.100). Therefore, the State is obligated to assist the Northwest Region to design and implement appropriate services.

2. In the Kotzebue Sound subregion, the Maniilaq Association contracts with the State to provide all human services except hospital care. Therefore, the Maniilaq Association is in a position to provide itinerant and local services in an administratively efficient manner. The Maniilaq Association could use its contractual experience to expand

the hiring and training of individuals to serve as homemakers and home health aides (home and family support specialists), with supervision through Maniilaq's Public Health Nursing program.

3. The Norton Sound Health Corporation oversees the community health aide program and the Norton Sound Regional Hospital. It is in a position to pursue contractual arrangements with the State, as the Maniilaq Association has done, so that in-home support services could be expanded beyond the homemaker services currently available in nine villages and very limited home health aide services available in Nome.

4. The Norton Sound area has a non-profit group, Bering Strait Human Services Council, specifically organized to plan and implement services for people with disabilities. This organization, with experience in operating Infant Learning in the subregion, has potential as a granting or contracting agency for other special community services.

5. Licensed day care services are available in Kotzebue, Nome, and Noorvik. Training could be made available to the service providers to assist them in caring for handicapped children and to encourage them to enroll such children.

6. The Bering Straits Infant Learning Program (ILP) bridges the gap in services between birth and school age. This service provides opportunities for some children to make up their developmental deficits prior to entering school. The ILP also supports parents in coping with their children's special needs, thereby reducing the risk of child abuse and neglect. The ILP, in conjunction with Norton Sound Family Services, has the opportunity to address both the educational needs of young handicapped children and the support and parenting skills needs of their parents. Parents can also be taught to provide appropriate kinds of stimulation to assist their infants to develop normally. In these ways, the ILP can promote child and family functioning, lessening stress and disorganization.

7. The Kotzebue Area Human Services Association (KAHSA) forms a basis for planning and case management in the Kotzebue Sound subregion. Through KAHSA, service providers can develop meaningful strategies for working together and with service users to strengthen and expand the service delivery system.

8. The three major school districts, Nome, Bering Straits, and Northwest Arctic, have special education directors and personnel and specialized support people available from ARMSI who can be used to improve the quality and extent of special education services in the region. The region has been a pilot site for developing services to deaf-blind and multihandicapped students. These resources can also help stimulate local community services.

9. The Beltz regional vocational school and higher education opportunities in Nome and Kotzebue can be used to develop training programs within the region for service workers and people with disabilities.

CHAPTER 7

THE CENTRAL REGION

Demographics

The Setting

The Central Region contains approximately 240,000 square miles, roughly 40% of Alaska's land mass. This huge area includes all the territory drained by streams flowing into the Tanana River from the Canadian border to its confluence with the Yukon River; the length of the Yukon River from the Canadian border to a point beyond Holy Cross; and the Upper Kuskokwim River drainage some distance north of its confluence with the Stony River. (Arctic Environmental Information and Data Center, 1975b) The Central Region is coterminous with the Doyon region.

For purposes of planning and service delivery, the Central Region is divided into seven subregions. These areas, with their locations, are as follows:

1. Fairbanks North Star Borough -- near the middle of the central region at the intersection of the Parks, Richardson, and Steese Highways; Fairbanks is the regional center.

2. Lower Yukon subregion -- the Innoko River and lower Yukon River areas near their confluence; Holy Cross is the subregional center.

3. Upper Kuskokwim subregion -- the territory of the headwaters of the Kuskokwim River and its various forks; McGrath is the subregional center.

4. Upper Tanana subregion -- the vast region from the Canadian border to the Fairbanks North Star Borough, north on the Taylor Highway to Eagle, and south to the Alaska Range; Tok is the subregional center.

5. Yukon Flats subregion -- the Yukon River area from Twelve Mile House north of Eagle to west of Beaver, including the Chandalar, Porcupine, and Black River drainages; Fort Yukon is the subregional center.

6. Yukon Koyukuk subregion -- the region around the confluence of the Yukon and Koyukuk Rivers from Ruby to Kaltag and Hughes to Koyukuk; Galena is the subregional center.

7. Yukon Tanana subregion -- the territory between the North Slope Borough boundary and Denali National Park, the Parks Highway communities southwest of Fairbanks, and the Tanana River area from Nenana to Tanana; Tanana is the subregional center.

Forms of transportation in this vast region vary from place to place. The highway communities from the Canadian border to Denali Park enjoy motor vehicle access year-round. Other communities on the Taylor, Elliott, and Steese Highways have motor vehicle access only during the summer. Fairbanks International Airport provides full service for jet traffic to and from Canada, Asia, Europe, the Lower 48, and dozens of points within Alaska. All the other communities have airstrips with varying capabilities, although most can handle only single- or twin-engine bush aircraft and some still lack runway lighting. The Yukon and Tanana Rivers are navigable for barge traffic, and they and most of the other rivers are traveled by small boat during the summer and by dogsled and snowmachine in the winter.

The People

The Central Region includes the Fairbanks North Star Borough, Southeast Fairbanks, and Yukon Koyukuk census areas. The combined population was 71,692 in 1981. Non-Natives make up the majority of the population in the region, although Athabaskans constitute the majority in many rural villages. The population in general is younger than that found in the south central region but older than elsewhere in Alaska. Only 38% of the people are under 21 years of age, although the average age is only in the mid-twenties. The rural communities have higher concentrations of children than does Fairbanks. (U.S. Department of Commerce, Bureau of the Census) Table 7-1 depicts the population of the central region by age and subregion. With an average annual growth from 1970 to 1981 of 2.30%, the region is expected to grow to 76,639 people in 1984 and 83,234 by 1988, as shown in Table 7-2. Appendix A contains population projections for 1984 and 1988 for the subregions of the Central Region.

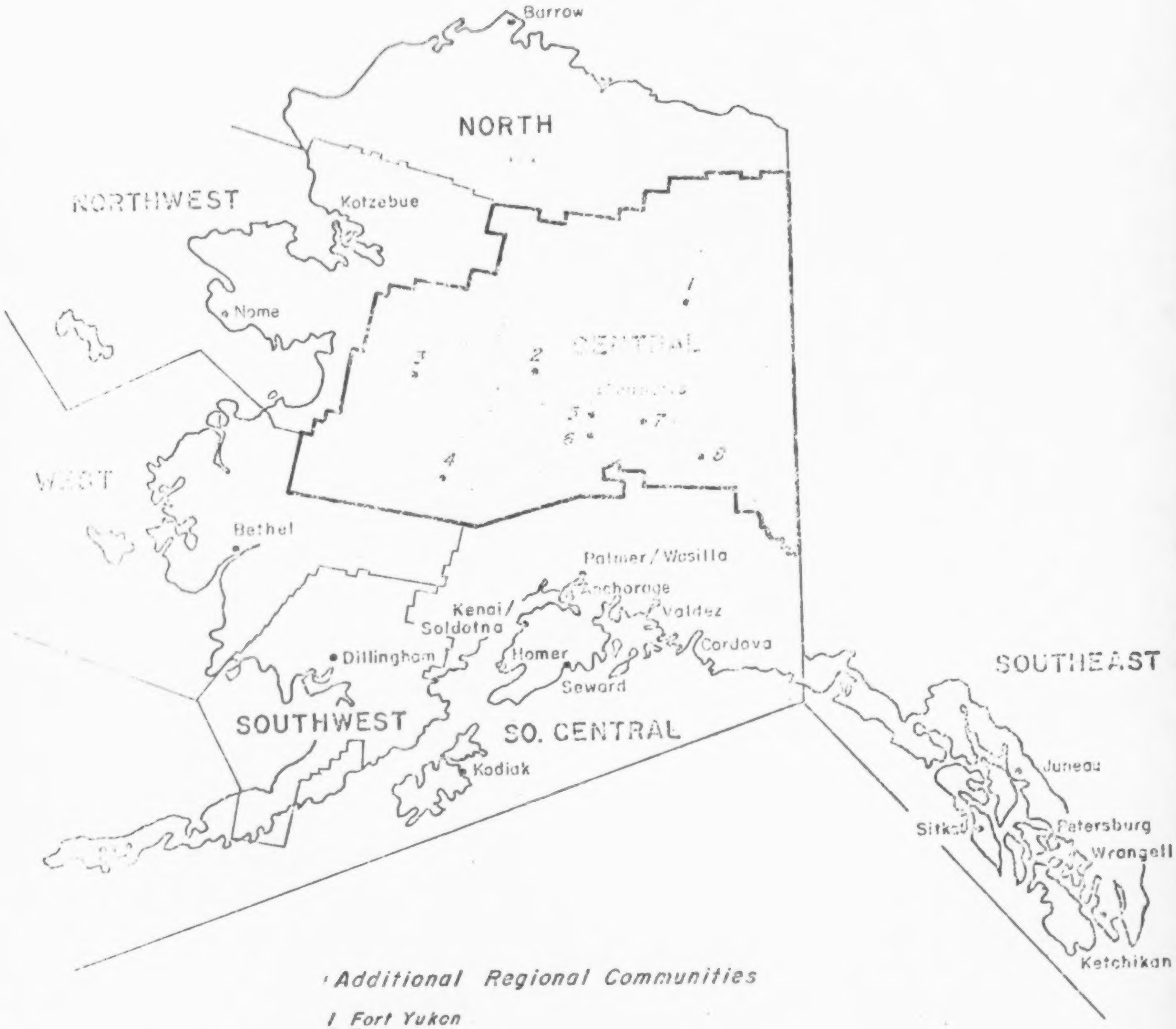
The Economy and Culture

The Central Region is an extremely diverse area, ranging from urban Fairbanks with its primarily non-Native, Western culture, to isolated rural villages where Native populations follow traditional subsistence lifestyles. This dichotomy between rural and urban areas is a significant one both culturally and economically.

Urban and Highway Communities

The economy of the urban and highway communities is chiefly oriented toward service, transportation, and mineral exploitation, along with tourism. For some years, the primary source of employment in Fairbanks has been government at all levels. The Trans-Alaska Oil Pipeline Development project created thousands of construction and petroleum-related jobs in Fairbanks, along the pipeline corridor, and in surrounding communities. The growing population caused increased needs for housing, for health, educational, shopping, and recreational facilities; and, for public utilities. Fairbanks is the goods and services center for northern Alaska and is a refueling point for trans-polar air traffic. (Alaska Department of Labor, 1983a)

CENTRAL REGION


Barrow
NORTH
NORTHWEST
Kotzebue
Nome
CENTRAL
Fairbanks
1
2
3
4
5
6
7
8
WEST
Bethel
Palmer / Wasilla
Anchorage
Kenai / Soldotna
Valdez
Dillingham
Homer
Cordova
Seward
SOUTHWEST
SO. CENTRAL
Kodiak
SOUTHEAST
Juneau
Sitka
Petersburg
Wrangell
Ketchikan

Additional Regional Communities

1 Fort Yukon
2 Tanana
3 Galena
4 McGrath
5 Nenana
6 Healy / Anderson
7 Delta Junction
8 Tok

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TABLE 7-1

POPULATION OF THE CENTRAL REGION BY AGE AND SUBREGION, 1980

	Population by Age Group					
Area	0-2	3-5	6-20	21-64	65+	Total
Fairbanks North Star Borough	3,444	2,948	13,474	32,474	1,276	53,983
Lower Yukon	42	40	194	391	28	695
Upper Kuskokwim	39	38	181	365	25	648
Upper Tanana*	388	377	1,561	3,208	142	5,676
Yukon Flats	73	70	338	679	47	1,207
Yukon Koyukuk	118	113	544	1,094	76	1,945
Yukon Tanana	204	196	945	1,901	132	3,378
TOTAL	4,308	3,782	17,604	40,112	1,726	67,532

* Coterminous with the Southeast Fairbanks census area.

Sources:

U.S. Department of Commerce, Bureau of the Census. 1980 Census of Population, General Population Characteristics, Part 3, Alaska. PC80-1-B3 Alaska. Washington, D.C. August 1982. Pp. 3-56, 3-57.

Alaska Department of Labor. Alaska Population Overview 1981. Juneau, Alaska. 1982. Pp. 11-17.

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TABLE 7-2

POPULATION OF THE CENTRAL REGION BY AGE GROUP,
1980 AND PROJECTED TO 1984 AND 1988

	Population by Year		
Age Group	1980	1984	1988
0-2	4,308	4,890	5,310
3-5	3,782	4,292	4,661
6-20	17,604	19,980	21,699
21-64	40,112	45,524	49,441
65+	1,726	1,962	2,131
TOTAL	67,532	76,639	83,234

Source:

U.S. Department of Commerce. Bureau of the Census. 1980 Census of Population, General Population Characteristics, Part 3, Alaska. PC80-1-B3 Alaska. Washington, D.C. August, 1982. Pp. 3-56, 3-57.

A large proportion (22.9%) of the population in the urban and highway communities is military-connected, either as active-duty personnel or dependents. The major bases are Fort Wainwright and Eielson Air Force Base in the Fairbanks North Star Borough and Fort Greely near Delta Junction. Numerous small installations are scattered throughout the rural areas. (Alaska Division of State Health Planning and Development, Northern Alaska Health Resources Association, South Central Health Planning and Development, and Southeast Alaska Health Systems Agency)

Rural Communities

Wage and salary employment is scarce in the rural Interior. All the subregions rely heavily on government as a source of employment. Both the Upper Tanana and Upper Yukon areas depend on government for as much as 70% of direct employment, and the Yukon Koyukuk area does for 38%. These rates compare to 32% for the state as a whole. (Alaska Department of Labor, 1983a)

None of the rural subregions have very well-developed secondary sectors, largely as a result of their small populations, causing them to depend on larger areas such as Fairbanks for many of their goods and services. The Upper Tanana and Yukon Tanana areas do have substantial service industries due to the fact that the Richardson and Parks Highways bisect these areas. Many of their inhabitants depend on the traffic for their livelihoods in the form of service stations, roadhouses, retail sales, and recreational facilities. (Alaska Department of Labor, 1983a)

Tourism provides very seasonal work, as reflected in the rural Interior's statistics. Employment in some subregions can fluctuate as much as 40% in one year, from the high summer quarter to the low winter quarter. Unemployment in the Upper Yukon census division has gone as high as 21% in the winter and dropped to 10% in August or September. All of the subregions' unemployment rates exceed the state average month after month. The average unemployment rate for the first eleven months of 1982 for the Upper Yukon, Yukon Koyukuk, and Southeast Fairbanks census areas were 13.7%, 13.5%, and 11.6%, respectively. Alaska's and Fairbanks' rates were 9.8% and 13.8% for the same period. (Alaska Department of Labor, 1983a)

Some employment that takes place in these rural areas is not recorded by official statistics because wages are not paid in the customary fashion. The two groups particularly affected are the small mining operators who are often self-employed and pay their help a percentage of the take and trappers who are compensated on a piece basis. (Alaska Department of Labor, 1983a)

The employment which does exist in these areas is in most cases concentrated in a few communities. For example, in the Upper Tanana subregion, 75% of the employment is in the Delta area, and most of the remainder is in Tok. In the Upper Yukon subregion, 80% of the employment is in Fort Yukon. The rest of the rural Interior's jobs are concentrated in the larger centers such as Nenana and Galena. (Alaska Department of Labor, 1983a)

Unlike Fairbanks, most of the rural communities get very little direct stimulus from North Slope activity. There are oil pump stations along the pipeline corridor, but employment in these facilities has been fairly stable since they were completed in 1977. Most of the stimulus to the economy has come from State government in the form of additional services, direct appropriations to local communities, and capital construction projects. Other special efforts such as the Delta agricultural project have added to the gradual economic upswing. Old stand-bys such as the military (Fort Greely, Anderson, Galena, Indian Mountain, and Campion) provide an important share of the job opportunities in the rural Interior. (Alaska Department of Labor, 1983a)

The trend of slow growth in the rural Interior is not expected to change in the near future. Employment will remain scarce, and unemployment will stay far above the state's average.

Social Problems

The major social problems in the Central Region are similar to those of the other regions. Alcohol abuse and its attendant effects dominate, with mental illness, suicide, child abuse and neglect, crime, and domestic violence all being significant causes for concern. Accidents are the leading cause of death and disability. (Northern Alaska Health Resources Association, 1982; Tanana Chiefs Health Authority)

The Target Population

As described in Chapter Two, all children who are substantially handicapped are considered to be developmentally disabled. These people make up about 3% of the age groups 0-2 and 3-5 and 1.87% aged 6-20. Adults are counted among the developmentally disabled only if their impairments arose in childhood. On the average, 1.49% of the population aged 21-64 and .5% aged 65+ are developmentally disabled. In addition, about 1.90% of the people aged 21-64 and 10% aged 65+ have other substantial limitations.

Table 7-3 summarizes the number of central region residents with substantial disabilities. Altogether, there were approximately 1,176 developmentally disabled and 935 otherwise disabled people in the central region in 1980. By 1983, those numbers are expected to rise to 1,452 and 1,152, respectively. Around 545 will comprise the school-aged (3-20) population. Tables 7-4a, b estimate numbers of substantially disabled people by age group for each subregion.

TABLE 7-3

ESTIMATED CENTRAL REGION POPULATION OF PERSONS
WITH SUBSTANTIAL HANDICAPS BY AGE AND CAUSE OF HANDICAP, 1980

	Persons with Substantial Handicaps, by Cause		
Age Group	Developmentally Disabled	Other	Total
0-2	129	0	129
3-5	113	0	113
6-20	329	0	329
21-64	598	762	1,360
65+	7	173	180
TOTAL	1,176	935	2,111

Sources:

U.S. Department of Commerce, Bureau of the Census. 1980 Census of Population, General Population Characteristics, Part 3, Alaska. PC80-1-B3 Alaska. Washington, D.C. August 1982. Pp. 3-56, 3-57.

Governor's Council for the Handicapped and Gifted. 1981-83 Alaska Developmental Disabilities State Plan. Fairbanks, Alaska. August, 1980. Pp. 25-29.

Urban Institute. Report of the Comprehensive Service Needs Study. DHEW-RSA. June 1975. Pp. 57-58, 72.

Older Alaskans Commission. Phone interview with Lawry Robertson. January 1983.

Methodology: See Appendix.

TABLE 7-4a

ESTIMATED SUBSTANTIALLY DISABLED POPULATION
FNSB

	Substantially Handicapped* Population		
Age Group	1980	1984	1988
0-2	103	120	131
3-5	88	103	112
6-20	259	309	328
21-64	1,101	1,277	1,395
65+	134	155	169
TOTAL	1,685	1,964	2,135

LOWER YUKON SUBREGION

	Substantially Handicapped* Population		
Age Group	1980	1984	1988
0-2	1	1	1
3-5	1	1	1
6-20	4	4	4
21-64	13	13	14
65+	3	3	3
TOTAL	22	22	23

UPPER KUSKOKWIM SUBREGION

	Substantially Handicapped* Population		
Age Group	1980	1984	1988
0-2	12	13	15
3-5	11	13	14
6-20	29	33	36
21-64	109	121	136
65+	15	17	18
TOTAL	176	197	219

* Includes both developmentally disabled and other disabled people.

Sources:

U.S. Department of Commerce, Bureau of the Census. 1980 Census of Population, General Population Characteristics, Part 3, Alaska. PC80-1-B3 Alaska. Washington, D.C. August 1982. Pp. 3-56, 3-57.

Governor's Council for the Handicapped and Gifted. 1981-83 Alaska Developmental Disabilities State Plan. Fairbanks, Alaska. August, 1980. Pp. 25-29.

Urban Institute. Report of the Comprehensive Service Needs Study. DHEW-RSA. June, 1975. Pp. 57-58, 72.

Older Alaskans Commission. Phone interview with Lawry Robertson. January 1983.

Northern Alaska Health Resources Association. Fairbanks, Alaska. 1983.

Methodology: See Appendix.

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TABLE 7-4b

ESTIMATED SUBSTANTIALLY DISABLED POPULATION

UPPER TANANA SUBREGION

Age Group	Substantially Handicapped* Population		
	1980	1984	1988
0-2	12	13	15
3-5	11	13	14
6-20	29	33	36
21-64	109	121	136
65+	15	17	18
TOTAL	176	197	219

YUKON FLATS SUBREGION

Age Group	Substantially Handicapped* Population		
	1980	1984	1988
0-2	2	2	2
3-5	2	2	2
6-20	6	6	6
21-64	23	23	23
65+	5	5	5
TOTAL	38	38	38

YUKON KOYUKUK SUBREGION

Age Group	Substantially Handicapped* Population		
	1980	1984	1988
0-2	4	3	4
3-5	3	3	3
6-20	10	10	10
21-64	37	36	37
65+	8	8	8
TOTAL	62	60	62

YUKON TANANA SUBREGION

Age Group	Substantially Handicapped* Population		
	1980	1984	1988
0-2	6	6	6
3-5	6	6	6
6-20	18	17	18
21-64	64	63	65
65+	14	14	14
TOTAL	106	106	109

* Includes both developmentally disabled and other disabled people.

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Community Descriptions

Fairbanks North Star Borough

The Fairbanks North Star Borough, a Level IV community, is the largest population center north of the Alaska Range, with 58,313 people in 1981. Almost 86% of the Fairbanks area's population is white; about 6% is Native; 5% black; and, the remainder Asian and other. Males make up 52.1% of the population. Almost 37.5% are under 21 years of age; only 2.4% are over 65. (U.S. Department of Commerce, Bureau of the Census; Alaska Department of Labor, 1982c)

The Borough is the major transportation, commercial, and service center for northern Alaska. Fairbanks International Airport handles all sizes of aircraft for passengers and cargo from international and domestic ports. Highways link Fairbanks with Anchorage, Prudhoe Bay, Canada and the Lower 48, and Haines, where ferries can be boarded for Southeast Alaska and Seattle. Water access is also possible via the Chena and Tanana Rivers. The Alaska Railroad runs from Fairbanks to Anchorage, with spurs to Eielson Air Force Base and Whittier.

The Greater Fairbanks community is composed of two cities--Fairbanks and North Pole--and numerous smaller settlements. Table 7-5 presents the 1980 population of the Borough by community.

Fairbanks is the center for the Fairbanks North Star Borough School District; the Doyon Native regional corporation; the Tanana Chiefs Conference; the Northern Regional Nursing Program of the Alaska Division of Public Health; the northern regional offices of the Alaska Division of Family and Youth Services, the Division of Mental Health and Developmental Disabilities, the Communicative Disorders Program, and the Division of Vocational Rehabilitation; the Governor's Council for the Handicapped and Gifted; the Northern Alaska Health Resources Association; and, the Interior Service Unit of the Alaska Area Native Health Service. The University of Alaska-Fairbanks, the Tanana Valley Community College, and the Cooperative Extension Service are also based in Fairbanks.

The various State and federal human service programs and the Tanana Chiefs Conference provide itinerant services to rural communities throughout the Interior and beyond.

Lower Yukon Subregion

The Lower Yukon subregion consists of Anvik, Grayling, and Holy Cross, clustered along the Yukon River just north of its confluence with the Innoko River, and Shageluk on the Innoko. This area, unlike the rest of the central region, relates more to Bethel and the southwest than to Fairbanks and the Interior. Within the Interior, the Lower Yukon villages look mainly to McGrath for assistance. The total population in 1980 was 695. Table 7-6 depicts the Lower Yukon population by village, as of 1980.

TABLE 7-5

POPULATION OF THE FAIRBANKS NORTH STAR BOROUGH*
BY COMMUNITY, 1980

Community	Population
Big Horn	360
College	4,043
Eielson	5,320
Ester	149
Fairbanks	22,645
Harding Lake	38
Moose Creek	510
Murphy Dome	72
North Pole	724
Salcha	319
Two Rivers	359
Remainder	19,321
TOTAL	53,983

* The Fairbanks North Star Borough, as a unit, is considered a Level IV community.

Source:

Tanana Chiefs Conference. 1983 Overall Economic Development Plan, Attachment 1. Fairbanks, Alaska. 1983. P. 9.

TABLE 7-6

POPULATION OF THE LOWER YUKON SUBREGION
BY VILLAGE, WITH COMMUNITY LEVELS, 1980

Village	Level of Community	Population
Anvik	I	114
Grayling	I	209
Holy Cross	I	241
Shageluk	I	131
TOTAL	-	695

Source: Alaska Department of Labor. Alaska Population Overview 1981. Juneau, Alaska. 1982. P. 17.

Holy Cross, with a 1980 population of 241, is the subregional center for the Lower Yukon area. It is the only Level I community in the Central Region to serve in that capacity. Holy Cross' population is 92% Native.

Anvik, the northern most village in the subregion, had a population of 114 in 1980. Its population was 80% Native.

Grayling, home of Grayling Air Service, is located between Holy Cross and Anvik on the Yukon River. Its 1980 population of 209 was 62% Native.

Shageluk is the only recognized village on the Innoko, although there are scattered mining camps which are occupied from time to time. Shageluk's population in 1980 was 131, of whom 92% were Native.

The Lower Yukon villages are served by the Iditarod Area School District and McGrath/Anvik Community and Family Services.

Upper Kuskokwim Subregion

The Upper Kuskokwim subregion is in the Kuskokwim River lowlands, bordered on the northwest by the Kuskokwim Mountains. The area is drained by the Kuskokwim, Big South Fork, North Fork, and Takotna Rivers. The area covers 14,400 square miles. (Tanana Chiefs Health Authority)

Although gold and silver mining were once predominant and a few mining operations continue, the major economic base for the subregion is subsistence hunting and fishing. Non-Natives in the area are either government employees or homesteaders.

The official population of the Upper Kuskokwim subregion was 648 in 1980, although there is substantial seasonal variation. Over 56% were males, and 51% were Native. This high concentration of males and non-Natives is due to the presence of 150 Federal Aviation Administration personnel in McGrath. (Tanana Chiefs Health Authority) Table 7-7 summarizes the population by village.

Access to the Upper Kuskokwim subregion is primarily by air, with service linking McGrath to Anchorage and Fairbanks almost daily. Grayling Air Service ties McGrath to the Lower Yukon subregion. Charter flights are available on bush aircraft from McGrath to other villages. During the summer, the villages within the subregion are accessible by water via the Kuskokwim River.

McGrath, a Level II community and the subregional center, is 150 miles due west of Mount Denali. It is 235 air miles southwest of Fairbanks and 190 air miles north of Anchorage. In 1980, McGrath had 355 residents, of whom 46.5% were Native.

Access to McGrath is primarily by air, while secondary summer access is possible via Bethel on the Kuskokwim River. Currently, four commercial carriers serve McGrath.

TABLE 7-7

POPULATION OF THE UPPER KUSKOKWIM SUBREGION
BY VILLAGE, WITH COMMUNITY LEVELS, 1980

Village	Level of Community	Population
McGrath	II	355
Medfra	I	25
Nikolai	I	91
Takotna	I	48
Tatalina Station	MR*	46
Telida	I	33
Other	Unassigned	50
TOTAL	-	648

*MR = military reservation; no community level designated.

Source: Alaska Department of Labor. Alaska Population Overview 1981. Juneau, Alaska. 1982. P. 17.

McGrath is a full-service village in that it offers almost all necessary amenities to its residents. The town has a mini-TV station, a grocery and general store, two hardware and sports stores, two air taxi services, a power and light company, a fire department, a fuel distribution and sales company, and a hotel and restaurant.

McGrath serves as the subregional headquarters for MTNT, Limited (a consolidated ANCSA village corporation), the Bureau of Land Management fire control project, the Iditarod Area School District, the Federal Aviation Administration, the Alaska Division of Aviation, the U.S. Weather Bureau, McGrath/Anvik Community and Family Services, and the Alaska Division of Public Health itinerant public health nurse.

Medfra is a small, unincorporated village on the right bank of the Kuskokwim River. The community is 245 air miles southwest of Fairbanks and thirty air miles east of McGrath. Access to the village is by small aircraft or by river in the summer. The population was approximately 25 in 1980 and is about 50% Native. Medfra has a small general store which operates somewhat sporadically. There is no electricity in Medfra, with the exception of private generators. Water is hauled in from the river or creek and sewage is disposed of through the privie system. This community does not have a health aide or any other trained providers. Residents have indicated that alcohol abuse and dental disease are their major health problems. (Tanana Chiefs Health Authority)

Nikolai is a second-class city located on the south fork of the Kuskokwim River 46 miles east of McGrath and 230 air miles southwest of Fairbanks. Nikolai is accessible by bush plane or by the river in summer. The population in 1980 was 91, of whom 90% were Native. The town has a general store, a school, a PHS water treatment plant, and electricity. Water is primarily hauled from the river, and sewage disposal is by privies. The major health problems include alcoholism, vision problems, dental disease, and mental health problems. (Tanana Chiefs Health Authority)

Takotna is an unincorporated village located on the Takotna River fourteen miles northwest of McGrath and 290 air miles southwest of Fairbanks. It is accessible by road from Sterling Landing on the Kuskokwim and is linked to approximately ninety miles of State roads. These roads connect Takotna with the settlements of Ophir, Gaines Creek, and Tatalina Air Force Station. Primary access to Takotna is by bush plane via McGrath or, in emergency situations, by larger planes at the Tatalina airstrip. The town is accessible by the river system during high water periods in the summer or overland in the winter. Takotna's 1980 population was 48, of whom 52% were Native. The main health problems are alcohol abuse, dental disease, eye problems, and intestinal infections from untreated water. (Tanana Chiefs Health Authority)

Tatalina Station is a military installation consisting of 46 Air Force personnel, all but one of whom are male and all of whom are non-Native.

Telida, an old Indian village, is located on the Swift Fork of the Kuskokwim River ninety miles northeast of McGrath and 170 air miles southwest of Fairbanks. In 1980, there were 33 residents, of whom 97% were Native. Primary access to Telida is by small aircraft, with secondary access by dogsled or snowmachine during the winter months. The town has no services other than a school. The major health problems are colds, flu, and skin diseases, especially in babies; dental disease; and, eye problems, especially refractive errors. (Tanana Chiefs Health Authority)

Upper Tanana Subregion

The Upper Tanana subregion is comprised of the area from the Canadian border along the Alaska Highway to the Fairbanks North Star Borough boundary, north on the Taylor Highway to Eagle, and south on the Glenn and Richardson Highways to the Alaska Range. Tok is the subregional center for the Native population and the communities in the easternmost reaches of the subregion. Delta Junction, a predominantly non-Native town and home to Fort Greely, serves as a commercial center for the areas near the intersection of the Richardson and Alaska Highways. Transportation in this subregion is mainly by motor vehicle and plane, although small boats, snowmachines, and dogsleds are also used.

The economy of the subregion is chiefly service and transportation centered, with State and federally-funded agencies employing numerous individuals. The tourist industry is a primary source of income. The oil pipeline cuts through this region, creating some jobs at pump stations.

The Upper Tanana subregion had 5,676 residents in 1980, of whom 55.8% were male and only 12.8% were Native. This preponderance of non-Natives and males is due to the presence of Fort Greely and the Trans-Alaska oil pipeline. Table 7-8 summarizes the 1980 Upper Tanana population by community.

Tok, a Level II community and the major subregional center, is located at the intersection of the Alaska and Glenn Highways, 206 miles southeast of Fairbanks and 325 miles northeast of Anchorage. The Canadian border is ninety miles to the southeast. The community began as a camp for the construction of the Alaska and Glenn Highways in 1942.

Tok is unincorporated and not within an organized borough. The economy is based on transportation, with tourism the major source of revenue in the private sector. State and federal agencies employ a number of people. Tok is the headquarters for the Alaska Gateway School District.

Tok is predominantly a non-Native community, with 84.7% of its 589 residents being non-Native. Major health problems include mental illness, alcohol abuse, accidents and injuries, dental problems, and upper respiratory infections. (Tanana Chiefs Health Authority)

Although Tok is linked to the major cities by the road system, the long distances and severe weather in winter keep this area isolated. Therefore, Tok's human services provide vital assistance to surrounding Level I communities.

TABLE 7-8

POPULATION OF THE UPPER TANANA SUBREGION BY VILLAGE, WITH COMMUNITY LEVELS, 1980

Village	Level of Community	Population
Big Delta	I	285
Chicken	I	37
Delta Junction	II	945
Dot Lake	I	67
Eagle	I	110
Eagle Village	I	54
Fort Greely	MR*	1,635
Healy Lake	I	33
Northway	I	73
Northway Village	I	112
Tanacross	I	117
Tetlin	I	107
Tok	II	589
TOTAL	-	5,676

* MR = Military reservation (no designated community level).

Source: Alaska Department of Labor. Alaska Population Overview 1981. Juneau, Alaska. 1982. P. 17.

Eight Level I communities are scattered around Tok. Chicken, Eagle, and Eagle Village are north of Tetlin Junction on the Taylor Highway and are accessible by road only during the summer. Dot Lake is located on the Alaska Highway fifty miles northwest of Tok. Tanacross is just north of the Alaska Highway between Tok and Dot Lake. Tetlin, Northway, and Northway Village lie south of the highway between Tok and the Canadian border.

Delta Junction, the other Level II community in the Upper Tanana subregion, is located at the intersection of the Alaska and Richardson Highways about halfway between Fairbanks and Tok. Delta Junction is a first-class city and, therefore, has its own school system, the Delta Greely School District. It is also the commercial center for neighboring Fort Greely, as well as for Big Delta and Healy Lake. Delta Junction's 1980 population was 945, of whom 53.8% were male and 97% were non-Native. (U.S. Department of Commerce, Bureau of the Census)

Yukon Flats Subregion

The Yukon Flats subregion lies along the Yukon, Chandalar, Porcupine, and Black Rivers and Birch Creek. The area extends from the Canadian Border to Beaver on the Yukon and up to Arctic Village in the north. The Venetie Reservation of about 1,808,000 acres includes Arctic Village and Venetie. In the south, the subregion extends to the Fairbanks North Star Borough boundary and includes Circle and Central on the Steese Highway. (Tanana Chiefs Health Authority)

Transportation is mainly by air out of Fort Yukon. Air North, Arctic Circle Air Service, and Wind River Air Service serve the subregion, and there are many private aircraft as well. Supplies are transported by barge in the summer. River barges serve Fort Yukon and Circle; smaller barges reach Chalkyitsik and Birch Creek. Venetie, Central, and Arctic Village have no barge access.

Four stores provide supplies by air to the subregion. Because of air transport of supplies, supplemented by barge transports, the cost of living in this subregion is at least sixty percent higher than in Anchorage. Many families rely on subsistence activities of hunting, trapping, and fishing. Future economic development may be in agriculture, timber, tourism, and mineral development.

The population of the Yukon Flats subregion was 1,207 in 1980. Over 56% were males; 76.6% were Native. Table 7-9 provides the Yukon Flats 1980 population by village.

Fort Yukon, a Level II community, had 619 residents in 1980, 71.4% of whom were Native. The community is located on the Yukon River at its junction with the Porcupine River. It is approximately 140 miles northeast of Fairbanks and serves as the center for air service to the subregion. Fort Yukon has a relatively stable economic base provided by the Yukon Flats School District, a military base, the Federal Aviation Administration, the Bureau of Land Management, and airline companies.

TABLE 7-9

POPULATION OF THE YUKON FLATS SUBREGION BY VILLAGE, WITH COMMUNITY LEVELS, 1980

Village	Level of Community	Population
Arctic Village	I	111
Beaver	I	66
Birch Creek	I	32
Central	I	36
Chalkyitsik	I	100
Circle	I	81
Fort Yukon	II	619
Venetie	I	132
TOTAL	-	1,207

Source: Alaska Department of Labor. Alaska Population Overview 1981. Juneau, Alaska. 1982. P. 17.

Other district offices in Fort Yukon which serve the subregion are the National Guard; the Alaska Division of Family and Youth Services; Alaska Department of Public Safety; and, the Tanana Chiefs Conference. Fort Yukon personnel provide itinerant health and social services to surrounding communities. Major health problems include alcohol and drug abuse, dental disease, family-centered problems, ear infections, upper respiratory infections, and skin diseases. (Tanana Chiefs Health Authority)

Five Level I villages look to Fort Yukon for health and social services, transportation, education, and commercial goods. These villages-Arctic Village, Beaver, Birch Creek, Chalkyitsik, and Venetie-orient to Fort Yukon for primary physical and mental health care and receive itinerant services from Fort Yukon, as well as from Fairbanks.

Arctic Village, on the east fork of the Chandalar River, is eighty miles from Venetie and 210 miles north of Fort Yukon. Its 1980 population of 111 was 88.3% Native.

Beaver, on the Yukon River, is sixty miles west of Fort Yukon and 110 miles north of Fairbanks. In 1980, Beaver had 66 residents, of whom 98.5% were Native.

Birch Creek, on the Lower Mouth Birch Creek, is 26 miles southwest of Fort Yukon. Its 1980 population was 32, of whom 96.9% were Native.

Chalkyitsik is located 45 miles northeast of Fort Yukon on the Black River. It is 170 air miles from Fairbanks. Of its 100 residents, 96% were Native.

Venetie, the second largest village in the region, had 132 residents in 1980, of whom 97.7% were Native.

In addition to these five traditional villages, there are two more Level I communities in the Yukon Flats subregion. Central, located on the Steese Highway, is largely (97.2%) a non-Native village. Its population of 36 is mainly employed in small-scale mining and in tourism related to nearby Circle Hot Springs. Circle, sixty miles upstream from Fort Yukon, is located at the eastern terminus of the Steese Highway, 130 miles from Fairbanks. Circle's 1980 population of 81 was 74.1% Native.

The Steese Highway through Central and Circle is generally open only in the summer. During that time, residents orient primarily to Fairbanks, bringing in their year's supplies by road. Circle residents also frequently go to Fort Yukon by boats, barges, and canoes. Both communities receive human services through the Yukon Flats subregion, with services and commercial goods supplemented through Fairbanks.

Yukon Koyukuk Subregion

The Yukon Koyukuk subregion extends from Ruby in the east, down the Yukon River to Galena, Koyukuk, Nulato, and Kaltag, and up the Koyukuk River to Huslia and Hughes in the north.

The subregion's population was 1,945 in 1980, of whom 73.4% were Native. Over half of the people are under 21 years of age. Table 7-10 depicts the subregion's 1980 population by village.

Two air taxi services operate out of Galena, providing daily flights to the surrounding villages, Fairbanks, and Tanana, and charter service when requested. Jet service is available twice weekly from Galena to Anchorage. During the summer, barge service is scheduled weekly. All communities in the region are accessible only by airplane or riverboat. Overland travel between villages by snowmachine or dogsled is common. There are no roads in this subregion.

The major health problems include mental illness, alcohol abuse; dental and eye problems; upper respiratory infections; otitis media; and accidents, particularly alcohol-related motorcycle and snowmachine mishaps. (Tanana Chiefs Health Authority)

Galena, the only Level II community in the subregion, is located on the Yukon River, 35 miles east of Nulato and 270 miles west of Fairbanks. Due to the availability of gravel, the military built an airfield and air force base in Galena, so that the village has a sizeable non-Native population. Of the 765 residents in 1980, 69.3% were male; only 45.8% were Native. (Alaska Department of Labor, 1982c)

Galena's economic base is fairly stable, in part because of the Air Force presence. Other major employers are the city, the Galena City School System, local stores, an RCA site, air services, and various federal and state agencies. Many residents are winter trappers and fish or fight fires during the summer. Commercial fishing is on the rise; subsistence fishing, hunting, and trapping are major food sources.

Galena has a water treatment plant connected to the school, clinic, city hall, and public safety building. Residents haul water in containers from the plant. Shower and laundry facilities are maintained by the Air Force in the old townsite. The City offers garbage pickup for a monthly fee.

The City of Galena built and holds the lease for the Galena subregional clinic. The clinic serves as a base for itinerant services to surrounding Level I villages.

Hughes is a small, isolated village surrounded by high mountains. It is on the east bank of the Koyukuk River in the Hogatza Highlands, 210 air miles northeast of Fairbanks. In 1980, the village population was 73, of whom 97.3% were Native.

Huslia, 100 miles down river from Hughes and 100 miles up river from Koyukuk, is 290 air miles from Fairbanks. The village's 1980 population of 188 was 94.7% Native.

Kaltag is located on the Yukon River, 33 miles southwest of Nulato and 335 air miles west of Fairbanks. It is the southern most village of the Yukon Koyukuk subregion. Of its 247 residents in 1980, 95.5% were Native.

TABLE 7-10

POPULATION OF THE YUKON KOYUKUK SUBREGION
BY VILLAGE, WITH COMMUNITY LEVELS 1980

Village	Level of Community	Population
Galena	II	765
Hughes	I	73
Huslia	I	188
Indian Mountain	MR*	27
Kaltag	1	247
Koyukuk	I	98
Nulato	I	350
Ruby	I	197
TOTAL	-	1,945

*MR = military reservation; no community level designated.

Kaltag is located on the Yukon River, 33 miles southwest of Nulato and 335 air miles west of Fairbanks. It is the southernmost village of the Yukon Koyukuk subregion. Of its 247 residents in 1980, 95.5% were Native.

Koyukuk lies on the Yukon River six miles downstream from the confluence with the Koyukuk River. It is sixteen miles northeast of Nulato and 290 air miles west of Fairbanks. In 1980, Natives constituted 73.4% of its population of 124.

Nulato, the second largest village in the subregion, is located on the Yukon River 25 miles west of Galena. Its 1980 population of 350 was 94% Native.

Ruby is on the Yukon River south of the junction with the Meloyitna River, 230 air miles west of Fairbanks. The closest town to Ruby is Galena, which is fifty miles downstream. Of 197 residents in 1980, 86.8% were Native.

Yukon Tanana Subregion

The Yukon Tanana subregion constitutes the middle of Alaska's Interior. It incorporates the territory between the North Slope Borough boundary and Denali National Park, the Parks Highway communities, and the Tanana River drainage from Nenana to Tanana.

Fairbanks is the goods and services center for this subregion. Anderson/Clear, Cantwell, Dunbar, Healy, McKinley Park, Nenana, Suntrana and Usibelli are linked to Fairbanks by the Parks Highway. Minto and Manley Hot Springs are accessible via the Elliott Highway. The remaining villages are accessible only by air and river in the summer. Flights from Fairbanks link all the communities directly to the city. Cargo is transported to Minto, Manley Hot Springs, and the Parks Highway communities on the highway system and to Wiseman Camp on the Dalton Highway. Freight is barged on the Tanana River from Nenana to Tanana and Manley Hot Springs. Allakaket/Alatna and Evansville/Bettles receive shipments only by air.

The economy of the Yukon Tanana subregion is predominantly tied to seasonal labor, construction, and firefighting; employment in Fairbanks; and, subsistence activities of fishing, hunting, and trapping. The larger communities of Nenana and Tanana offer somewhat more employment opportunities for their residents.

The Trans-Alaska oil pipeline affected the residents of this area greatly, with employment and close proximity of the pipeline to several villages. The Dalton Highway and utility corridor pass through Wiseman Camp and near Evansville/Bettles. The use of this corridor as well as the Gates of the Arctic National Park will directly affect this region in the future. It is expected that recreational use of the land will increase to a great extent, affecting the economy and the demand for services. (Alaska Department of Labor, 1983a)

The population of this subregion was 3,378 in 1980. About two thirds of these people were non-Natives; however, away from the highway communities, Natives were in the majority (78.5%). Table 7-11 presents the 1980 population for the Yukon Tanana subregion and each of its villages.

The major health problems of this subregion include alcohol and drug abuse, accidents and injuries, upper respiratory infections, otitis media and other ear problems, dental disease, eye problems, nutrition problems, sexually transmitted diseases, skin disease, and mental health problems.

Within this subregion, there are three service centers other than Fairbanks:

1. Nenana and the Parks Highway south to Clear.
2. Evansville/Bettles, the transportation hub and minor service center for Allakaket/Alatna, Wiseman Camp, and Anaktuvuk Pass (a North Slope Borough village), and several mining camps and homesteading communities.
3. Tanana, the Tanana Chiefs Conference subregional service center.

Nenana, a Level II community, is located on the Parks Highway at the confluence of the Nenana and Tanana Rivers, sixty miles from Fairbanks. Nenana, as a first-class city, operates the Nenana City Schools. It is also the headquarters for the Yukon Koyukuk School District, the Nenana Native Council, and the Toghotthele Native Corporation. Nenana is the subregional center for the Parks Highway communities. Nenana's 1980 population was 470, 54.5% of whom were non-Native.

Healy, although not a subregional center, is the location of the Railbelt School District offices. Healy's 1980 population of 334 was almost totally (94.9%) non-Native.

Evansville/Bettles, a Level I community, 190 air miles northwest of Fairbanks on the Koyukuk River, is made up of Bettles Field and Evansville, one-half mile downstream. Bettles Field was built in 1945 to support the exploration of Naval Petroleum Reserve #4. The Federal Aviation Administration airfield still provides the major source of income. Because of the airfield, Evansville/Bettles is a commercial and cargo center for Allakaket/Alatna, Wiseman Camp, and Anaktuvuk Pass. Evansville/Bettles had 94 residents in 1980, of whom 71.3% were non-Native.

Tanana, a Level II community, is located on the Yukon River a short distance downstream from the junction of the Tanana and Yukon Rivers. Fairbanks is 130 miles to the east, and Galena is 145 miles to the west. Historically, Tanana was a meeting and trading site for members of the Tanana, Kutchin, and Koyukuk tribes. In 1941, the United States Public Health Service built a hospital in Tanana, and the village became the health service center for the rural Interior. Although the hospital closed in 1982, Tanana remains a human service center for the subregion and the commercial center for Rampart and Stevens Village. As a first class city, Tanana operates the Tanana City Schools. Tanana also is the headquarters for the Toyitna Native Corporation and the subregional offices of the Tanana Chiefs Conference. Tanana's 1980 population of 388 was 79.1% Native.

Service Flow Patterns

Seen as a whole, the Central Region has one major service center, Fairbanks, surrounded by six subregions, each with one or more subregional centers. While the six subregions are largely separate from each other, they are all bound to Fairbanks. Within each subregion, every Level I community relates to its subregional center, usually a Level II community, for goods and services. The general flow of persons seeking services would be from his home community (Level I) to the subregional center, and then on to Fairbanks.

TABLE 7-11

POPULATION OF THE YUKON TANANA SUBREGION
BY VILLAGE, WITH COMMUNITY LEVELS 1980

Village	Level of Community	Population
Allakaket/Alatna	I	163
Anderson/Clear	I	517
Campion Station	I	62
Cantwell	I	89
Dunbar	I	50
Evansville/Bettles	I	94
Healy	I	334
Manley Hot Springs	I	61
McKinley Park	I	32
Minto	I	153
Nenana	II	470
Rampart	I	50
Stevens Village	I	96
Suntrana	I	56
Tanana	II	388
Usibelli	I	53
Other	Unassigned	710
TOTAL	-	3,378

Source: Alaska Department of Labor. Alaska Population Overview 1981. Juneau, Alaska. 1982. P. 17.

Available Services

Health Services

Health services in the Central Region range from very limited services in Level I villages to highly sophisticated opportunities in Fairbanks, the regional center and a Level IV community. There are four major types of service providers in the region: 1) the Indian Health Service; 2) the Alaska Public Health Service; 3) the military; and, 4) the private sector.

The Indian Health Service operates the Interior Service Unit, which is based in Fairbanks. The Alaska Native Health Center provides a full range of outpatient medical, dental, and public health nursing services in the Fairbanks clinic, with itinerant services to the rural Interior.

The Alaska Public Health Service, including the Northern Regional Nursing Program, serves all of the Interior. The Fairbanks Health Center provides comprehensive public health nursing and home health services within the North Star Borough, including satellite well-child clinics at Two Rivers, Salcha, and North Pole. The Northern Regional program, also based in Fairbanks, sends public health nurses on an itinerant basis to many Level I communities and oversees nurses stationed in Fort Yukon, McGrath, Galena, Delta Junction, and Tok.

The military operates the Bassett Army Community Hospital on Fort Wainwright, the Eielson Clinic at Eielson Air Force Base, and the Fort Greely Clinic at Fort Greely. These facilities serve military personnel and their dependents from all of northern Alaska.

In the non-profit private sector, the Tanana Chiefs Conference oversees the community health aide (CHA) program for the rural Interior. Each Level I community now has at least one health aide, and many have alternate health aides as well. The Tanana Chiefs Conference also operates clinics and mental health and alcoholism services in several subregional centers, as well as a hostel in Fairbanks for rural residents who must come to town for services not available in their home communities.

The City of Galena, which has health powers, runs the Galena Health Center, which provides physician assistant and public health nursing services for Galena and the Yukon Koyukuk subregion. The City of Tanana also has assumed health powers and has taken over the old Tanana Public Health Service Hospital, which now is an outpatient clinic and senior citizens residence.

Fairbanks Memorial Hospital is the regional tertiary care facility, now operating 145 beds and providing almost all diagnostic and treatment services. The hospital includes adult medical and surgical services, pediatrics, obstetrics, psychiatric services, emergency services, diagnostic radiation services, laboratory, blood bank, cardiac and intensive care services, and neonatal special care.

Careage North, a proprietary skilled/intermediate care facility in Fairbanks, has 101 beds. The Pioneers' Home, operated by the State of Alaska primarily as a residential care facility for older Alaskans, has 46 of its 119 beds designated for nursing care.

The Central Region has 71 physicians in private practice, six associated with the U.S. Public Health Service, and 23 in the military. The Tanana Valley Medical and Surgical Group in Fairbanks also operates physicians assistant clinics in Delta Junction, Nenana, and Tok. There were 27 dentists in private practice in the Central Region in 1981, with four others in the Public Health Service, nineteen in the Army, and one with the National Health Service Corps in Galena.

Table 7-12 summarizes the health services provided in each community of the Central Region.

Support Services

Support services are those services which are needed in addition to adequate medical care, educational and vocational services, and employment opportunities in order for a substantially disabled person to live independently or with his/her family. There are three major types of support services--maintenance services, living skills training services, and material support services. Table 7-13 summarizes the support services available in the Central Region.

Maintenance Services

During FY 1983, there were approximately 1,650 licensed day care "positions" available to children in the Fairbanks North Star Borough, located in both day care homes and day care centers. Such services were available also in McGrath, Delta Junction, Fort Greely, and Tanana, and informal arrangements for sitter services were present in most other communities.

The Alaska Department of Community and Regional Affairs operates the Day Care Assistance Program to help economically stressed families to offset the high cost of child care in some communities. This program supplemented child care payments for a total of 1,399 families in the Fairbanks North Star Borough, Delta Junction, Fort Greely, McGrath, and Tanana in FY 1983. Among this group were three substantially disabled children. The total budget for the Day Care Assistance Program in the Central Region was $1,195,500, with an average cost per child of $850. The total dollars spent on day care for disabled children was $2,564.

In addition to generic day care services, an estimated 91 families in the Fairbanks North Star Borough area need respite care/specialized sitter services for their substantially handicapped members. The Fairbanks Rehabilitation Association (FRA) offers respite care to developmentally disabled and other substantially disabled people. In FY 1982, FRA's respite care program served 53 substantially handicapped families for a total of 17,476 hours of care. Care is provided to a maximum of 24 individuals at a time and may be given in the respite care center/apartment or in the person's own home. The average cost per hour of service was $10.72 in FY 1982, when the total budget was $187,500. In FY 1983, the respite care budget was $165,580; the FY 1984 request is $205,580.

HEALTH SERVICES AVAILABLE IN THE CENTRAL REGION OF ALASKA, by COMMUNITY, 1983

		Prevention					Early Identification											
Community	Level	PC	SHE	PA	WCP	I	PNT	MDS	VHS	MTS	D&E	MS	DS	OT	PT	SSH	HHN	HHA
Fairbanks North Star Borough	IV	L	L		L	L	L	L	L	L	L	L	L	L	L	L	L	L
Lower Yukon Subregion																		
Anvik	I		L		L	L		I	I			I	I			I		
Cravling	I		L		L	L		I	I			I	I			I		
Holy Cross	I		L		L	L		I	I			I	I			I		
Shageluk	I		L		L	L		I	I			I	I			I		
Upper Kuskokwim Subregion																		
McGrath	II		L		L	L		L	L			L	I			I		
Medfra	I		I		I	I												
Nikolai	I		L		L	L		I				I	I			I		
Takotna	I		L		L	L		I				I						
Tatalina Station	MR***																	
Telida	I		L		L	L		I				I						
Big Delta	I																	
Chicken	I																	
Delta Junction	II	L	L		L	L		L	L		L	L	L			I		L
Dot Lake	I	L			L	L		I	I			I	I			I		
Eagle	I																	
Eagle Village	I																	
Fort Greely	MR		L															
Healy Lake	I																	
Northway	I	L			L	L		I	I			I	I					
Northway Village	I																	
Tanacross	I	L			L	L		I	I			I	I					
Tetlin	I	L			L	L		I	I			I	I					
Tok	II	L			L	L		I	I			I	I					
Yukon Flats Subregion																		
Arctic Village	I	L			L	L		I	I			I	I					
Beaver	I	L			L	L		I	I			I	I					
Birch Creek	I	I			I	I		I	I			I	I					
Central	I																	
Chalkyitsik	I	L			L	L		I	I			I	I					
Circle	I	L			L	L		I	I			I	I					
Fort Yukon	II	L			L	L		I	I		I	I	I			I		
Venetie	I	L			L	L		I	I			I	I					
Yukon Koyukuk Subregion																		
Galena	II	L			L	L		L	L		I	L	L			I		
Hughes	I	L			L	L		I	I			I	I					
Huslia	I	L			L	L		I	I			I	I					
Indian Mountain	MR																	
Kaltag	I	L			L	L		I	I			I	I					
Koyukuk	I	L			L	L		I	I			I	I					
Nulato	I	L			L	L		I	I			I	I					
Ruby	I	L			L	L		I	I			I	I					
Yukon Tanana Subregion																		
Allakaket/Alatna	I	L			L	L		I	I			I	I					
Anderson/Clear	I	L	L		L	L		L	L			L						
Campion Station	MR																	
Cantwell	I																	
Dunbar	I																	
Evansville/ Bettles	I	L			L	L		I	I			I	I					
Healy	I	L	L		L	L		L	L			L						
Manley Hot Springs	I	L			L	L		I	I			I	I					
McKinley Park	I																	
Minto	I	L			L	L		I	I			I	I					
Nenana	II	L			L	L		L	L			L	I					
Rampart	I	L			L	L		I	I			I	I					
Stevens Village	I	L			L	L		I	I			I	I					
Suntrana	I																	
Tanana	II	L			L	L		L	I			L	I					
Usibelli	I																	

I = Itinerant
PC = Prenatal care
SHE = School health education
PA = Public awareness
WCP = Well-child program
I = Immunizations
PNT = Prenatal Testing

L = Locally-based
MDS = Medical/developmental screening
VHS = Vision and hearing screening
MTS = Metabolic screening
D&E = Diagnosis and evaluation of handicapping conditions
MS = Medical services

DS = Dental services
OT = Occupational therapy
PT = Physical therapy
SSH = Speech and hearing services
HHN = Home health nursing
HHA = Home health aide services

Sources: Northern Alaska Health Resources Association. Health Resource Development Plan for Northern Alaska, 1982. Fairbanks, Alaska. April, 1982.
Tanana Chiefs Health Authority. Tanana Chiefs Conference, Inc., Regional Health Systems Plan, Subregional Health Resources. Fairbanks, Alaska. 1979.

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Homemaker services provide household assistance, chore service, and/or non-medical personal assistance to enable a person and his/her family to live at home. The Alaska Division of Family and Youth Services (DFYS) contracts with Alaska Management Technologies to provide homemaker services statewide. However, services currently are not offered in many communities. Twenty-one communities in the Central Region had homemaker services available in FY 1983. Level II communities which had no service were Nenana and McGrath. A number of Level I communities also lacked service. Altogether, 308 people in the Central Region received homemaker services in FY 1983; of these 308, 38 were considered substantially handicapped. Clients received an average of 95.8 hours of care each, at a total cost of approximately $1,169. The total cost of homemaker service for substantially disabled people for the year was $44,422.

Home health aide support is a special resource made available to individuals who need health-related personal care in order to maintain an independent, community-based living arrangement. Home health aide services were provided to fifty clients in Fairbanks, Delta, and Nenana in FY 1983 through the Alaska Division of Public Health. The cost per client was $1,760, for a total of $87,975. The proportion of the clients who were substantially handicapped is unknown.

Fairbanks Home Health Care, a part of the Fairbanks Health Center and administered by the Alaska Division of Public Health, Section of Nursing, provides skilled nursing and therapy services in the home in the Fairbanks area. Services are provided free of charge to all persons who have physicians' orders for such care. During FY 1983, Fairbanks Home Health Care provided skilled nursing services to 155 individuals, sixteen of whom were substantially handicapped. The average cost per client was $1,180. The total budget for FY 1983 was $182,859, of which $18,880 was spent on care of the substantially disabled.

While there is some need for personal aide and attendant care in the Central Region, particularly in Fairbanks, such care is not currently available.

In the Fairbanks North Star Borough, the Municipal Area Transit System runs scheduled bus service with vehicles having wheelchair lifts. These lifts are frequently out of service and, at any rate, handicapped persons have difficulty getting to the bus stops. The Borough's Parks and Recreation Department operates portal-to-portal van service for handicapped people who participate in its recreation programs. In the near future, the Transit System plans to take over the transportation function of that program from the Parks and Recreation Department and to contract for the provision of "dial-a-ride" services for the handicapped. The only other transportation services offered to the disabled are provided by the School District, the Fairbanks Rehabilitation Association, and other agencies as adjuncts to their larger programs. Outside of the Fairbanks area, no local transportation services other than those provided by school districts or senior citizens programs are available.

An average of 80 people with handicaps participated in the program every week in FY83. From September through May attendance averaged 94 people. One of the reasons attributed to the high attendance and success of the program is inclusion of accessible door-to-door transportation for participants. Participants doubled when transportation was provided. When the Borough's Transit System assumes that function, Parks and Recreation will retain the use of their van, which has a lift, for week-end recreation programs. (Fairbanks North Star Borough Parks and Recreation Department, 1983.)

Programs include Special Olympics training in winter and summer sports. Bowling, swimming, nordic skiing, track and field, physical fitness, and team sports are part of the training program. Local, regional and state Special Olympic Games are held annually. In 1983 Fairbanks hosted the state games and 358 people competed. The Special Olympics Games are for people with mental retardation.

The Borough also has aquatic programs for people with physical disabilities and a cultural "accessibility" program to help people attend cultural events and concerts. A wheelchair basketball program was started in 1982-83 but has not continued due to lack of interest. Horseback riding is offered twice a week all summer and there is a waiting list of people wanting to take part. Wilderness camping is scheduled every week-end in July and August for people age eight and older.

Next year the Borough will being the "Play to Grow" program developed by the Kennedy Foundation. "Play to Grow" is a recreation program for families who have a disabled member.

The FY83 budget of $124,000 covered transportation and programs with 90% of the funds used for staff, all but the Director on a part-time basis. Programs have been offered at no cost. When at least five people express interest in a sport of activity, the Parks and Recreation Department tries to provide a program. (Fairbanks North Star Borough Parks and Recreation Department, 1983.)

Fairbanks North Star Borough School District provides summer school for special education students whose Individual Education Programs specify a need for service year-round. In the summer of 1983, 125 students took part in three schools, Ryan, North Pole, and Birch. Programs included field trips and other opportunities for development of social, and independent living skills as well as the usual special education and related services.

In the smaller communities Special Olympics training is run by the school's special education department or by special education teachers. The Tanana VAlley Special Olympics includes Fairbanks, Nenana, and Ft. Yukon. Tok has its own local Special Olympics area program. In rural parts of the Central Region, no recreation programs especially designed for disabled people are available outside of the schools.

Developmental Services

Developmental services such as personal or family counselling and training, are provided by the school districts, the Fairbanks Rehabilitation Association, Vocational Rehabilitation, the Community Mental Health Center, and other programs as adjuncts to or part of their other program services. The Fairbanks North Star Borough's summer camping program for disabled children is the only major activity of its kind in the Central Region.

Material Support Services

Cash assistance is available to eligible individuals and families in the Central Region on the same basis as elsewhere in the state. The major categories of special assistance to the handicapped are Aid to the Disabled and Aid to the Blind, through the Alaska Division of Public Assistance, and Supplemental Security Income (SSI) payments, in accordance with the federal Social Security Act.

Personal adaptive equipment is provided to disabled children through Alaska's Handicapped Children's Program. The State Division of Vocational Rehabilitation supplies personal and environmental equipment and home retro-fits for disabled adults who have vocational rehabilitation potential. Voluntary health agencies such as the Multiple Sclerosis Society have "loaner" equipment or, in some cases, will purchase and install environmental adaptive equipment for individuals who meet their eligibility criteria. For other people, particularly adults with little vocational potential, adaptive equipment is generally unavailable except through private or third-party payment or on an informal basis.

Residential Services

Services Available in the Central Region

Over 95% of the disabled people in the Central Region live in their own homes and the natural environment. For the other 5%, Fairbanks offers augmented, devised, and protective residential environments for its residents and for people from other parts of the state. Options range from subsidized adoptions to skilled nursing care.

Augmented environments which were utilized in the Central Region in FY 1983 include specialized foster care and the apartment program, both through the Fairbanks Rehabilitation Association, and subsidized adoption, administered by the Alaska Division of Family and Youth Services.

The Fairbanks Rehabilitation Association's (FRA) Specialized Foster Care Program provides alternatives to institutionalization for severely disabled young people. Through the program, individuals are placed in foster homes for a minimum period of eighteen months. Foster parents receive extensive training concerning the specific aspects of the disabled person's program. On-going staff support is provided to the families, in addition to a stipend. During FY 1983, three persons were placed in specialized foster care in Fairbanks. One of these people was from the Central Region; the other two were from the South Central and Northwest Regions. All cam to the program from Harborview Developmental Center in Valdez. Funding limits this option to four clients annually.

TABLE 7-13

SUPPORT SERVICES AVAILABLE IN THE CENTRAL REGION, FY 1983

Type of Service	Availability*	Substantially Handicapped Clients Served	Average Cost Per Client	Total Costs for Handicapped Clients
MAINTENANCE SERVICES				
Day Care/sitter	P	NR	NR	NR
Day Care Assistance Program	P	3	$855	$2,564
Respite/specialized sitter	P	53	$10.72/hour	$165,580
Homemaker	P	38	$1,169	$44,422
Home health aide	P	NR	$1,760	NR
Home health nursing	P	16	$1,180	$18,880
Personal aides and attendants	U	--	--	--
Transportation	P	NR	NR	NR
Recreation	P	NR	NR	NR
LIVING SKILLS TRAINING SERVICES	P	NR	NR	NR
MATERIAL SUPPORT				
Financial Assistance	A	NR	NR	NR
Environmental adaptive equipment	P	NR	NR	NR
Personal adaptive equipment	P	NR	NR	NR

* A = available; P = available in only some parts of the region; U = unavailable; NR = not reported.

Sources:
Alaska Department of Community and Regional Affairs, Division of Employment Opportunity. Day Care Assistance Programs Mid Year Summary. FY 1983. Juneau, Alaska. February, 1983.
Alaska Department of Community and Regional Affairs, Division of Employment Opportunity. Unpublished data concerning the day care assistance grant program, FY 1983. Juneau, Alaska. March, 1983.
Alaska Department of Health and Social Services, Division of Family and Youth Services. Computer print-out on homemaker services program utilization. Juneau, Alaska. December, 1982.
Alaska Department of Health and Social Services, Division of Public Health, Section of Nursing. Home Health Aide Services, FY 1983. Juneau, Alaska. May 17, 1983.
Alaska Management Technologies. Correspondence with the Governor's Council for the Handicapped and Gifted. Juneau, Alaska. May 17, 1983.
Bergerson, Lois. Home Health Case Load. Correspondence with Dorothy Truran of the Governor's Council for the Handicapped and Gifted. Juneau, Alaska. May 17, 1983.
Fairbanks Rehabilitation Association. FY83 DD Proposal. Submitted to the Alaska Division of Mental Health and Developmental Disabilities. Fairbanks, Alaska. May, 1982.
Fairbanks Rehabilitation Association. Summary of Activities, Fiscal Year 1982, July 1981 through June 1982. Fairbanks, Alaska. July, 1982.
Governor's Council for the Handicapped and Gifted. Respite Care Providers Survey. Fairbanks, Alaska. December, 1982.
Governor's Council for the Handicapped and Gifted. 1983 Priorities for Gifted and Talented Students in Alaska Schools and for People with Disabilities and their Families. Fairbanks, Alaska. February, 1983.

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FRA's Apartment Program provides residential alternatives within the community as well as independent living skills training. The program has two components -- an independent apartment option and a transitional apartment option. While an individual is in the transitional program, staff members work with him or her to develop the shopping, housecleaning, transportation, and related skills that will be needed for living independently. In the independent apartment option, participants are virtually independent in all aspects of daily living. In FY 1983, six people participated in FRA's apartment program. Four of these people were residents of the Central Region. The other two were from the Southeast and Northwest Regions. The program has a capacity of fourteen.

The Alaska Division of Family and Youth Services (DFYS) offers subsidized adoptions to enable placement of children who require medical services beyond the financial abilities of their adoptive families. During FY 1983, there was one child in the Central Region who was in a subsidized adoptive placement.

The DFYS also provides foster care for fourteen substantially disabled children and youth in the Central Region. These children were not so impaired that they required specialized foster care. Of the fourteen children placed in the Central Region in 1983, eleven were residents of the Central Region prior to their placements. One was from the northwest region; the home communities of the other two children were not identified on available records.

Devised environments are usually small group settings (5 or less people) especially established and operated by an agency. FRA offers the only devised residential service in the Central Region through its Adult Group Homes. FRA's program operates three homes, which are dispersed throughout Fairbanks. Two of the homes have capacities of five beds, and one, a tri-plex has, eight people in the different apartments. During the first six months of 1983, nineteen people lived in these facilities. Nine of the clients were residents of the Central Region prior to their participation in the Group Home program. Seven clients were from the South Central Region, one was from the Northwest Region, and two were from out of state.

Protective environments are only appropriate for people who need 24-hour care to protect them from harm. Careage North Health Care Center, the only protective residential environment in the region, offers skilled and intermediate nursing services in its 101-bed facility in Fairbanks. In FY 1983, sixteen residents of Careage North fit the definition of "substantially disabled." Eight of these people were residents of the Central Region prior to their admission. Four were from out of state, and one each were from the South Central, Southwest, Western, and Northern regions. Careage North is a nursing home, and convalescent care center which serves mostly aging people.

Table 7-14 shows utilization experience of residential facilities/programs in the Central Region, by home region of the clients.

Facilities Utilized by Residents of the Central Region

During FY 1983, thirteen residents of the Central Region received care in augmented environments. One child in the age group 0-5 participated in FRA's specialized foster care program; another young child was placed in the Central Region through the State's subsidized adoption program. In the 6-20 age group, one individual received services from Anchorage's ARMSI-Satellite Home Program; four others were placed through the Hope Cottages Foster Care Program in Anchorage. Two adults took part in the Hope Cottages Independent Living Program in Anchorage; four other adults remained in Fairbanks with FRA's apartment program.

During the same time period, thirteen other residents of the Central Region were in devised environments. This group included two school-aged children in the Hope Cottages Children's Group Home Program in Anchorage. There were nine adults in the FRA Group Home in Fairbanks and one each in the Hope Cottages Adult Group Home in Anchorage and the Gateway Opportunity Center Group Home in Ketchikan.

There were more people in protective environments than any other form of residential placement. Altogether, there were 23 developmentally disabled and six otherwise disabled people from the Central Region in five different protective settings in FY 1983.

Table 7-15 outlines all the residential placements of residents of the Central Region during FY 1983.

Residential Service Needs of Central Region Residents

In the Central Region, as Table 7-16 shows, an estimated 65 individuals needed some form of residential assistance in FY 1983. Twenty-three people received this care in their home region; 27 remained without service. As with the other regions, there is some discrepancy between numbers needing service and numbers receiving it. There are more people in protective environments than projection methods and provider assessments would indicate is appropriate.

Cost of Residential Services Provided in the Central Region

Augmented environment programs are generally the least costly form of residential service. In FY 1983, the State budgeted $237,714 for the care of substantially handicapped persons in augmented environments in the Central Region. This total covered an average daily cost per recipient of $27.14. As Table 7-17 shows, however, different augmented environments require substantially different expenditures. The least costly program is subsidized adoptions, at an average cost of $9.87 per recipient day. The most expensive is specialized foster care, at a daily cost of $101.44 per recipient.

Devised environment programs, as a rule, are more expensive than augmented environments but less so than protective environments. In FY 1983, the State budgeted $317,870 for services for persons with substantial handicaps living in devised environments, for an average daily cost per recipient of $45.84. The only program in the Central Region which falls within this category is the FRA Group Home. Operating funds came from the State General Fund ($212,332) and from State Revenue Sharing and Federal SSI payments to clients ($105,538).

The Careage North Health Care Center in Fairbanks is the only protective setting for handicapped people in the Central Region. State General Fund monies match federal Title XIX Medicaid monies dollar for dollar, for an average daily rate of $103.35 per intermediate care resident. The total FY 1983 budget for Careage North for sixteen disabled clients was $603,564.

TABLE 7-14

UTILIZATION OF CENTRAL REGION RESIDENTIAL FACILITIES, BY HOME REGION OF CLIENTS WITH SUBSTANTIAL HANDICAPS, FY 1983

	Number of Clients by Home Region									
Program by Type of Environment	SE	SC	C	SW	W	NW	N	Out of State	Unknown	Total
AUGMENTED										
DFYS Foster Care	0	0	11	0	0	1	0	0	2	14
DFYS Subsidized Adoption	0	0	1	0	0	0	0	0	0	1
FRA Apartment Program	1	0	4	0	0	1	0	0	0	6
FRA Specialized Foster Care	0	1	1	0	0	1	0	0	0	3
DEVISED										
FRA Adult Group Home	0	7	9	0	0	1	0	2	0	19
PROTECTIVE										
Careage North	0	1	8	1	1	0	1	4	0	16
TOTAL, ALL ENVIRONMENTS	1	9	34	1	1	4	1	6	2	59

Source: Governor's Council for the Handicapped and Gifted. Surveys of Provider Agencies, January - June, 1983. Fairbanks, Alaska. July, 1983.

TABLE 7-15

RESIDENTIAL PLACEMENTS OF CENTRAL REGION RESIDENTS WITH SUBSTANTIAL HANDICAPS, FY 1983

Program by Type of Environment	Location	Number of Residents by Age Group				
		0-5	6-20	21-64	65+	Total
AUGMENTED						
ARMSI Satellite Home Program	Anchorage	0	1	0	0	1
FRA-Specialized Foster Care Program	Fairbanks	1	0	0	0	1
Hope Cottages Foster Care Program	Anchorage	0	4	0	0	4
Hope Cottages Independent Living Program	Anchorage	0	0	2	0	2
FRA Apartment Program	Fairbanks	0	0	4	0	4
DFYS Subsidized Adoption Program	Central Region	1	0	0	0	1
DEVISED						
Hope Cottages Children's Group Home	Anchorage	0	2	0	0	2
Hope Cottages Adult Group Homes	Anchorage	0	0	1	0	1
FRA Group Homes	Fairbanks	0	0	9	0	9
Gateway Opportunity Center Group Home	Ketchikan	0	0	1	0	1
PROTECTIVE						
Nakoyia Health Care Center	Anchorage	0	0	5	0	5
Wesleyan Nursing Home	Seward	0	0	2	0	2
Careage North	Fairbanks	0	0	8	0	8
Harborview Developmental Center	Valdez	0	1	9	0	10
Hope Cottages ICF-MR	Anchorage	0	3	1	0	4
TOTAL		2	11	42	0	55

Source: Governor's Council for the Handicapped and Gifted. Survey of Provider Agencies, January - June, 1983. Fairbanks, Alaska. July, 1983.

TABLE 7-16

NUMBERS OF SUBSTANTIALLY HANDICAPPED PERSONS NEEDING AND RECEIVING RESIDENTIAL PLACEMENTS, CENTRAL REGION, 1983

	Number of People				
Placement by Age Group	Needing Service	Receiving Service in Home Region	Receiving Service Outside Home Region	Unserved	Unserved in Home Region
AUGMENTED ENVIRONMENT					
0-5	5	2	0	3	3
6-20	7	0	5	2	7
21+	16	4	2	10	12
All ages	28	6	7	15	22
DEVISED ENVIRONMENT					
0-5	4	0	0	4	4
6-20	5	0	2	3	5
21+	13	9	2	2	4
All ages	22	9	4	9	13
PROTECTIVE ENVIRONMENT					
0-5	3	0	0	3	3
6-20	2	0	4*	[2]	2
21+	10	8	17*	0[15]	2
All ages	15	8	21*	3[14]	7
TOTAL	65	23	32*	10	42

* More people are placed in protective environments than would appear to need such care.
[] People over-served in protective who are estimated to need less restrictive placements.

Source: Governor's Council for the Handicapped and Gifted, FY 81-82 DD State Plan. Fairbanks, Alaska. Chapter 6.
Surveys of provider agencies. January, 1983.
Analysis of special education and residential placement data. June, 1983.

TABLE 7-17

COSTS AND FUNDING SOURCES FOR RESIDENTIAL SERVICES PROVIDED IN THE CENTRAL REGION, FY 1983

Facility/Program	Funding Source	FY 1983 Budget for Services to Persons with Substantial Handicaps	Average Daily Cost Per Handicapped Resident
AUGMENTED			
DFYS Foster Care	State General Fund	$83,804	$16.40
DFYS Subsidized Adoptions	State General Fund	3,600	9.87
FRA Apartment Program	State General Fund	39,234	17.92
FRA Specialized Foster Care	State General Fund State Revenue Sharing	101,626 9,450	101.44
AUGMENTED, Subtotal	All Sources	237,714	27.14
DEVISED			
FRA Group Homes	State General Fund State Revenue Sharing and Federal SSI	212,332 105,538	45.84
DEVISED, Subtotal	All Sources	317,870	45.84
PROTECTIVE			
Careage North	Title XIX State General Fund	301,782 301,782	103.35
PROTECTIVE, Subtotal	All Sources	603,564	103.35
GRAND TOTAL, ALL SETTINGS		$1,159,148	$53.83

Sources: Governor's Council for the Handicapped and Gifted. Survey of Provider Agencies, January - June, 1983. Fairbanks, Alaska. July, 1983.
Alaska Department of Health and Social Services, Division of Public Assistance. Monthly Nursing Home Census and Per Diem Rates. Juneau, Alaska. 1983.

Educational Services

Infant Learning Program

Infant learning programs (ILP) in the Central Region were started in Fairbanks by Project TEACH. A federal three year grant was awarded to Alaska Crippled Children and Adults to demonstrate the effectiveness of early intervention and infant stimulation for handicapped and high-risk children. This program helped lead the way for Infant Learning Programs in other Alaskan communities.

Project TEACH offers weekly home-based training like the other ILPs. In addition, for children over eighteen months of age a center-based program is also provided. Parents come with their children to a central location for a half day session twice a week.

PROJECT TEACH SERVICE MODES

Home-based program only	Home-based; also some center-based when large equipment is needed, but still in the 1:1 relationship (therapist:family)	Primarily center-based with parents attending and at least one home visit per month (Home-based only if needed)	
Birth	18 months	24 months	3 years

Project TEACH staff-an early childhood specialist; occupational, physical, and speech therapists; and a parent-child coordinator-work with each parent and child. The program philosophy is:

> "That a multidisciplinary approach is essential for effective treatment. The past four years of program experience have made it clear that children usually require the expertise of at least one discipline in addition to a general education service, and many children require the help of several disciplines. The interdisciplinary approach is also of great benefit for staff training. Each staff member becomes more effective through the knowledge he gains by daily association with the other disciplines." (Alaska Crippled Children and Adults, Project TEACH, ILP Grant Proposal for F84. Fairbanks, February, 1983.)

Most of the other ILPs in Alaska utilize personnel external to the program for the multidisciplinary evaluations and specialized services. Project TEACH serves Delta, Nenana, and the highway communities, as well as the Fairbanks North Star Borough.

In the Fairbanks Infant Learning Program, approximately 20% of the "graduates" do not require continuing special education services. With serial testing using the Alpern-Boll Developmental Profile, 40% have made substantial gains. In addition, 23% have made significant improvements. (Ibid.)

In FY82, 121 infants were enrolled in Project TEACH, and the combined home-based and center-based programs were funded at $249,000. FY83 saw a 12% budget cut which should be restored and added to for a budget of over $250,000 in FY84.

The Tanana Chiefs Conference, a private non-profit regional Native corporation, provided ILP services to the balance of the Central Region for the past three years. An itinerant service model is utilized with two teacher/specialists based out of the Chiefs' headquarters in Fairbanks.

Emphasis has been on screening all children in Tanana Chiefs region in order to identify children needing services. Another focus has been on providing training and information on parenting and special needs of handicapped children to families and health workers.

In FY82, eighteen children were enrolled in the Tanana Chiefs program and 155 were screened. The program was funded by the Alaska Division of Public Health at $183,000. For FY84, Tanana Chiefs will not be the contractor for services unless an agreement is reached between TCC and Public Health on the allowable indirect cost to be charged. The State may re-issue its request for proposals for infant learning services in the Tanana Chiefs area.

Meanwhile, the McGrath-Holy Cross area has developed its own ILP proposal and will be awarded $54,000 to hire a teacher and provide ILP services locally in McGrath and on an itinerant basis to the surrounding villages. Under the Tanana Chiefs organization, program personnel had to travel from Fairbanks to McGrath and beyond by way of Anchorage. Travel time and costs contributed to mobilization of locally-based services under the McGrath Education and Mental Health Center.

Pre-School

Head Start programs serve 3- to 5-year old children. There are four programs at seven sites in the Central Region. Fairbanks has 80 children enrolled, with nineteen of those identified as handicapped. The Tanana Chiefs Conference has programs at four locations serving a total of 76 children, ten of whom are handicapped because of speech and language delay or impairment. Galena's Head Start program serves seventeen and Huslia's ten.

The Fairbanks North Star Borough School District has 97 children enrolled in pre-elementary programs. Sixty-six are in half-day programs, twenty attend a special school for the handicapped, and eleven are in resource rooms part-day. Each of the six REAA's has identified handicapped 3-5 year-olds and provides services. Of the three LEAs, other than Fairbanks, none reported children served in this age group.

TABLE 7-18

CENTRAL REGION
INFANT LEARNING PROGRAM ENROLLMENT STATISTICS, FY 1982

			Disabled Children				ILP Utilization				Funding (in thousands)		
Community	Agency	Total Pop. 0-2 FY80	At Risk	DD	Screened Svd	Enrolled	T	MDE	Contact Hours	Number Home Visits	FY82	FY83	FY84
Fairbanks	Alaska Crippled Children and Adults	3,444	172	103	141	121	70	121	3,825	1,292	249.9	220.0	250.0
Upper Kuskokwim & Lower Yukon	McGrath Education Mental Health	39	2	0	0	0	0	0	0	0	0	0	54.6
Tanana/Yukon/Koyukuk		825	41	25	155	18	5	7	398	73	183.8	134.1	--
TOTAL		4,308	215	128	296	139	75	128	4,223	1,365	433.7	354.1	304.6

DD = developmentally delayed; T = terminated; MDE = received multi-disciplinary evaluations.

Sources: Division of Public Health, Infant Learning Program Year-End Report, FY82. Anchorage, Alaska. September, 1982.
Division of Public Health, FY84 budget allocations, Infant Learning Program Coordinator. Anchorage Alaska. August, 1983.

BIA's five schools do not have funding and do not provide services for this age group.

Identified children could be served through Head Start programs or through the State Department of Education's Centralized Correspondence program.

Special Education

Special education services for handicapped children are provided in each of the local districts (LEAs), regional school districts (REAAs), and BIA schools. Table 7-19 details the student enrollments and exceptionality categories by school agency. A total of 1,766 special education students were served in the 1982-83 school year. These children represented 12% of the total school enrollments.

Thirty students were served out-of-district (Table 7-20), including 23 from Fairbanks and one or two from the smaller school systems. Four districts had no out-of-district placements. The Fairbanks figure, 23, includes ten students in the correctional system at the Youth Detention Center in Fairbanks and four at Anchorage's McLaughlin Youth Center. Four Fairbanks students were served out-of-state at a cost to the State Department of $153,000. One returned to the state during the year.

Alaska Resources (ARMSI) provided specialized outreach services to help districts serve 25 severely handicapped students locally. The ARMSI services were not available or utilized in the region's BIA schools.

All districts purchase some external resources on an itinerant basis to meet special needs for psychological testing and speech, physical, and occupational therapy. Consultants are also utilized to develop special programs such as services for emotionally disturbed children and to offer in-service training to teachers and aides. Teacher aides play an important part in service delivery and in individualizing instruction as data show there is one aide for every two or three special education teachers. Costs and funding for special education students in the Central Region are shown on Tables 7-21 and 7-22.

Vocational Services

"Vocational services" is the term applied to the activities which assist a person in preparing for, securing, and maintaining employment. Some of the services are geared to school-aged children; others are more appropriate for adults. People with substantial handicaps need the same basic set of career- and employment-oriented services as does the general population. The focus and intensity of services provided to people with substantial handicaps may be a bit different from those provided to the general population, but the goal of using these services remains the same - employment.

TABLE 7-19

1982-83 SPECIAL EDUCATION ENROLLMENT INFORMATION
CENTRAL REGION

School District	Number of Schools	Total Enroll-ment	Number of Sp Ed Students	% of Total Enroll-ment	Exceptionality											
					MR	HH	D	SI	VH	SED	OI	OHI	SLD	DB	MH	Out of District
LEAs																
Fairbanks	28 [a]	12,012	1,210	10	62	9	6	370	6	24	15	2	706		10	23##
Galena	2	140	20	14				8					12			
Nenana	2	214	45	20				15		3	3		24			1
Tanana	1	88	18	20	1			3					14			
REAAs																
Alaska Gateway	6	447	94	21	2			46					46			1
Delta/Greely	3	835	157	26	4	4	1			3	7	3	134		1	
Iditarod	9	335	39	12	6			10					22		1	
Railbelt	4	334	47	14				19					28			1
Yukon Flats		353	48	14	2			15					29		2	2
Yukon-Koyukuk		399	63	16	2			22				1	38			3
BIAs																
Beaver		20	4	20									4			
Grayling		42	4	10				2					2			
Shageluk		20	1	5	1											
Tetlin		20	8	40									8			
Venetie		47	8	17									8			
TOTALS		15,306	1,766**	12	80	13	7	510	6	30	25	6	1,075	0	14	31

** Does not include out-of-district

Includes students in the Youth Detention Center and Presbyterian Hospitality House.

a) Includes 255 special education students enrolled in schools on military bases in the Fairbanks North Star Borough.

MR = Mentally Retarded
HH = Hard of Hearing
D = Deaf
SI = Speech Impaired
VH = Visually Handicapped
SED = Seriously Emotionally Disturbed
OI = Orthopedically Impaired
OHI = Other Health Impaired
SLD = Specific Learning Disability
DB = Deaf/Blind
MH = Multiply Handicapped

Sources: Alaska Department of Education. 1982-83 School Year, P.L. 94-142, P.L. 89-313 Counts. Juneau, Alaska. 1983.
U.S. Department of the Interior, Bureau of Indian Affairs, Anchorage Office. Data Search. Anchorage, Alaska. May, 1983.

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TABLE 7-20

CENTRAL REGION
1982-83 SCHOOL YEAR OUT-OF-DISTRICT PLACEMENTS

	Level of Home Comm.				Age Range				Exceptionality						Total Placements
Program Placement	I	II	III	IV	3-5	6-12	13-15	16-21	MR	D	SED	OI	SLD	MH	
Fairbanks															
Out-of-State				4				4			1			3	
Hospitality House				1				1						1	
Anchorage Mental Health Program				2		1	1							2	23
State School for Deaf				2		1		1		2					
McLaughlin				4			2	2					4		
Fairbanks Youth Detention Center				10			2	8			10				
Nenana															
Anchorage Mental Health Program		1					1		1						1
Yukon Flats															
Anchorage Mental Health Program	1							1						1	2
McLaughlin		1						1					1		
Railbelt															
McLaughlin		1					1						1		1
Alaska Gateway															
Anchorage Mental Health Program		1				1							1		1
Yukon-Koyukuk															
Anchorage Mental Health Program	2					1	1							2	2
TOTALS	3	4		23		4	8	18	1	2	11		7	9	30

MR = Mentally Retarded
OI = Orthopedically Impaired
D = Deaf
SLD = Specific Learning Disability
SED = Seriously Emotionally Disturbed
MH = Multiply Handicapped

Sources: Alaska Department of Education, Office for Exceptional Children. Juneau, Alaska. March, 1983.
Program Surveys, Governor's Council for the Handicapped and Gifted. Fairbanks, Alaska. June, 1983.

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TABLE 7-21

1982-83 SCHOOL YEAR FUNDING FOR SPECIAL EDUCATION PUBLIC SCHOOLS CENTRAL REGION

	FY83 Funding Sources					
	Foundation Funding					
School District	Reg. Ed. Allotment	Special Ed. Allotment	Total	P.L. 94-142 Funding	P.L. 89-313 Funding	Total Funding
LEAs						
Fairbanks	4,123,651	6,133,176	10,256,827	164,785	176,715	10,598,327
Galena	163,102	131,594	294,696	3,451		298,147
Nenana	231,837	152,820	384,657	7,765		392,422
Tanana	114,430	131,594	246,024	3,106		249,130
REAAs						
Alaska Gateway	593,618	407,520	1,001,138		65,142	1,066,280
Delta/Greely	896,683	916,920	1,813,603		108,801	1,922,404
Iditarod	519,917	263,188	783,105		27,027	810,132
Railbelt	438,084	254,700	692,784		32,571	725,355
Yukon Flats	631,651	263,188	894,839		33,264	928,103
Yukon-Koyukuk	809,528	460,579	1,270,107		43,659	1,313,766
TOTAL	8,522,501	9,115,279	17,637,780	179,107	487,179	18,304,066

Sources: Alaska Department of Education, Division of Education Program Support. FY83 P.L. 94-142 and P.L. 89-313 Distribution Calculations, unpublished data. Juneau, Alaska. January, 1983.
Alaska Department of Education, Division of Management, Law, and Finance, Public School Foundation Program Calculations, March 2, 1983.

TABLE 7-22

1982-83 SCHOOL YEAR FUNDING FOR SPECIAL EDUCATION PUBLIC SCHOOLS AND BIA SCHOOLS CENTRAL REGION

	FY83 Funding Sources					
	Funding					
Schools	3017 Funds	3101 Funds	Total	P.L. 94-142 Funding	P.L. 89-313 Funding	Total Funding
BIAs						
Beaver	8,112	4,988	13,100			
Grayling	1,948	4,988	6,936			
Shageluk	10,355	1,247	11,602			
Tetlin	8,696	9,975	18,671			
Venetie	11,929	9,975	21,904			
TOTAL BIAs	41,040	31,172	72,212			72,212
	Reg. Ed.	Special Ed.	Total			
Total LEAs	4,633,020	6,549,184	11,182,204	179,107		11,538,026
Total REAAs	3,889,481	2,566,095	6,455,576		310,464	6,766,040
TOTAL PUBLIC SCHOOLS	8,522,501	9,115,279	17,637,780	179,107	487,179	18,304,066
TOTAL PUBLIC AND BIA SCHOOLS	8,563,541	9,146,451	17,709,992	179,107	487,179	18,376,278

Source: U.S. Department of the Interior, Bureau of Indian Affairs, Anchorage Office. Data Run. Anchorage, Alaska. June 1, 1983.

Fairbanks Rehabilitation Association

The Fairbanks Rehabilitation Association (FRA) provides pre-vocational training in work habits such as attendance, endurance, punctuality, quantity, quality, interpersonal relations, and work experiences. The agency also conducts individual client evaluations of vocational interest and progress on pre-vocational work experiences; time studies; and evaluation of clients' strengths, weaknesses, skills, and potential for finding employment. Included in the vocational evaluations are basic function tests, psychometric tests, formal work samples, and situational assessments.

A major component of FRA's vocational program is vocational placement, primarily through FRA Industries, a sheltered workshop in Fairbanks. The sheltered workshop is designed for developmentally disabled people who have a potential and willingness to achieve a level of self-supporting employment. For clients who progress to a level of competency beyond that required in the sheltered workshop, FRA seeks out placements in competitive employment. Clients placed in competitive jobs are provided vocational follow-along services, which include a work adjustment program to aid them in development of appropriate work habits, eye-hand coordination, tool usage, communication skills, and other skills necessary to success on the job.

FRA's pre-vocational training, vocational placement, and vocational follow-along services have a capacity of thirty clients at any given time.

Alaska Vocational Services

Alaska Vocational Services (AVS) provides basic evaluation, in-house testing, and work tryouts. The average length of time in service for each client is three- to four-weeks. AVS also provides work adjustment/vocational follow-along service for clients placed in competitive employment situations by the Alaska Division of Vocational Rehabilitation. Their service capacity in Fairbanks in FY 1983 was twelve.

Adult Learning Programs of Alaska

The Adult Learning Center in Fairbanks provides pre-vocational coping and literacy skills to trainable clients defined as mentally retarded, hard of hearing, deaf, visually handicapped, seriously emotionally disturbed, orthopedically impaired, or other health-impaired adults. In FY 1982, this program served 75 clients with its $68,700 grant from the Alaska Department of Education, Office of Adult and Continuing Education.

Division of Vocational Rehabilitation

The Alaska Division of Vocational Rehabilitation (DVR) is the major vocational agency of State government. DVR is charged under P.L. 93-112 and A.S. 23.15.010 with providing a full range of vocational evaluation, counseling, training, job placement, and follow-along services. These services are available through an office in Fairbanks, which also provides itinerant services to Fort Yukon, Barrow, Kotzebue, and Nome and supervises rural services provided through the Kenai office. Some of DVR's services are provided through other agencies, such as FRA and Alaska Vocational Services, on a contractual basis.

The DVR also conducts pre-vocational evaluations for students enrolled in the Fairbanks North Star Borough School District secondary schools.

The Fairbanks office of DVR, which serves west, northwest, and central Alaska, saw 296 clients in FY 1982.

School Districts

The school districts in the Central Region provide career and vocational education, pre-vocational training, and vocational training as components of the regular school curriculum. The numbers of approved vocational courses offered by each district in the 1982-83 school year were: Alaska Gateway-33; Delta-Greely-52; Fairbanks North Star Borough-145; Galena City-25; Iditarod Area-40; Nenana City-26; Railbelt-37; Tanana City-21; Yukon Flats-27; and, Yukon Koyukuk-45. These services and courses are provided to all interested students and are not designed especially for the substantially handicapped.

Enabling Services

Case Management Services

Informally, case management functions are carried out by particular agencies currently providing services to a disabled person and his or her family. For families involved in Project TEACH, for example, the Infant Learning staff is looked to for guidance, information, and advice by the families and other agencies. The teacher may also assist, with family approval, in making referrals, planning, and obtaining, other needed services. Community health aides are the local, resident village health professionals who also serve this function for many, also on an informal basis as an adjunct to health care responsibilities. Division of Family and Youth Services Social Workers also assist in case management as part of their provision of protective or other family services. Fairbanks Rehabilitation Association's direct service personnel have a major role as case managers for clients, especially for those in residential programs.

There is no formal case management "system" for people with disabilities, just as there is no such system for the general population or for other population sub-groups. For most services to be provided, however, there are requirements for individual case service planning, development of habilitation, rehabilitation, special education, or family service plans, which is the primary responsibility of the providing agency in consultation and coordination with other related service or health personnel.

Guardianship Services

Guardianship and conservatorship services for people who are disabled and incapacitated can only be provided for legally after following a process of filing a petition and having a hearing in Superior Court. Since guardianship, responsibility for the person and making decisions for the person, and conservatorship, management of the person's finances, mean that some or all of the disabled or incapacitated person's legal rights are taken away, special legal proceedings must take place to make sure that rights are not taken away without due process and without basis.

The Fourth Judicial District includes the Central Region Superior Court is held in Fairbanks and petitions may be filed and heard there. State law provides that a visitor must be appointed to investigate the situation of the person for whom a guardian is sought, to see if guardianship is necessary to protect the individual, and to identify people who might serve as guardian. If the Court determines that guardianship is necessary and that there is no relative or friend to be guardian, the Court can assign the Public Guardian to handle the person's affairs. First priority, however, is given to family and friends. According to the public guardian at the Court System in Fairbanks they may be appointed as co-guardians when families are distant from relatives in nursing homes so that the public guardian can contact the family and personally carry out their decisions. This cooperative system is reported to be working well.

Staff Training and Manpower Development Services

Each agency has responsibility to provide for staff training. P.L. 94-142 requires training of teachers and other special education personnel. Title VI-B funds are provided to school districts based on special education enrollment and are utilized for training as well as child find activities. The special education outreach program, ARMSI, provides training to local people on an itinerant basis. The Division of Family and Youth Services has a training center in Anchorage for social workers employed by the Division. The Division of Public Health provides health education and training and sets aside money for annual training of infant learning program teachers.

Agencies often open training sessions to other service personnel and the public at large. The University of Alaska and Tanana Valley Community College offer semester and short courses. The office of Conferences and Institutes at the University offers 2 to 3 day workshops very frequently. Information and Referral

In the Central Region information about services and referral to services takes place informally and formally. Each service provider has a portion of the over-all responsibility to explain services, answer questions, make referrals, and coordinate with other workers and people in the community. A great deal of coordination is required in the Level I and II communities because of the use of itinerant services. This means that local people must plan and coordinate schedules, trips, flights, and meetings between people in the villages such as the health aides as well as with itinerant providers who may be coming from Fairbanks, Anchorage, or beyond. At this point in time there is no over-all coordination of health and social services information and referral. Fairbanks Crisis Line compiles service information across all services in the North Star Borough and operates a 24-hour service, including special information and referral for people with disabilities such as hearing impairments.

Protection and Advocacy Services

Protective services are provided by the Division of Family and Youth Services. Legal services are available on a resident basis in Fairbanks and on an itinerant basis to the villages by Alaska Legal Services Corporation. Private attorney services can be obtain from Fairbanks and Anchorage. The state Ombudsman's Office in Fairbanks accepts and investigates complaints about state agencies.

The only agency providing specialized protection and advocacy services to remedy violations of rights or due process, and to seek redress through negotiation, administrative, and legal means, and to provide assistance to disabled individuals who cannot access services themselves, is Protection and Advocacy for the Developmentally Disabled (P.A.D.D.). An advocate in Fairbanks can receive inquiries and provide services in the Central Region. Legal services are provided by PADD's attorney from Anchorage.

PADD served eighteen individuals in the Central Region during the first nine months of FY83. Thirteen were from Fairbanks. The remaining five were in villages in the Yukon Flats and Yukon-Tanana Sub-regions. Ten complaints dealt with special education. Other complaints (one each) were concerned with employment, finances, criminal justice, rehabilitation, habilitation, abuse/exploitation, and housing. Eight complaints were resolved.

Obstacles and Opportunities

Obstacles

Every region has characteristics of geography, economics, population size, attitudes, and values which can present challenges in human service delivery. Many of these obstacles are similar from area to area; others are unique to particular regions or villages. Almost every problem can be overcome through dedication and creativity on the part of community residents. The following obstacles to service delivery for the handicapped have been identified in the Central Region:

1. The physical environment poses great challenges to regionwide service systems. The wide dispersal of people, long distances, and difficult travel conditions make it important to develop support competencies at the local level.

2. The small population size of the Central Region outside of the Fairbanks North Star Borough causes the provision of certain kinds of services not to be feasible. There are not enough clients to share overhead costs, nor can providers maintain their technical skills with so few people to serve.

3. The Central Region has no centralized plan for service development. Although the Tanana Chiefs Conference adopted a tribal specific health plan in 1979, that plan is outdated and was never comprehensive in terms of needs of the disabled. Other plans, such as those

by the Northern Alaska Health Resources Association and the Arctic Alliance for People, only partially fill the gaps.

4. Lack of services in the past contributed to inappropriate placements of some clients and no services for others. There are now people in residential placements outside of their home communities who could be returned if adequate support services were available. Community services are needed, especially support services and placements in augmented environments. Many people from other regions are served in the Central Region's residential programs. Some Central Region people are placed out-of-region. Funding mechanisms favor protective placements. Funds are not available to develop and support augmented and devised residential options even though there are waiting lists of people referred for service, and even though provider surveys indicate that protective settings are not necessary.

5. In some cases, community residents have attitudes which work against the development of local placements for severely disabled people. Positive attitudes and awareness of what can be accomplished locally must precede community acceptance and action.

6. Services to rural areas are fragmented because there are multiple providers and funding sources. The Tanana Chiefs Conference, the Alaska Public Health Nursing Program, the Indian Health Service, state agencies, various school districts, non-profit programs, and private practitioners all serve the Interior. While this arrangement usually works well in Fairbanks and is desirable in some cases in the rural communities, it can disrupt continuity of care and result in overlapping services or gaps in services for particular villages or individuals within villages.

7. Providers need to develop a functional way for people from different agencies to plan together with individual disabled people and their families. There is no established way of creating a shared sense of a person's home situation and a shared vision of a person's possibilities. Consequently, responses are more fragmentary than they need to be, and there is less empowerment of existing support networks than is possible. Services developed without a strong sense of a person's context will miss many opportunities.

8. In-home services face numerous obstacles in rural areas. Funding is inadequate for homemaker services and virtually non-existent for home health services. The actual need for in-home services is not known or sufficiently documented in many villages. Training for homemakers and home health aides is insufficient, and trainers are generally unavailable. There is considerable "red tape" involved in obtaining services in many cases, and villages often lack personnel to assist clients with the paperwork.

9. Pre-school services are experiencing severe constraints because of physical-plant inadequacies, particularly in Fairbanks. The Greater Fairbanks Area Head Start Association badly needs a new building in a location more accessible to the community.

Opportunities

The planning process enables communities to change obstacles into opportunities. Concerned service providers, clients, family members, and other interested people can work together to solve problems and implement community change.

Several opportunities in the area of services for the handicapped are now available in the Central Region:

1. State law requires the State to plan, develop, and implement a comprehensive system of services and facilities for the handicapped (A.S. 47.80.100). Therefore, the State is obligated to assist the northern region to design and implement appropriate services. The Governor's Council has sponsored service planning activities in the region and can help provide technical assistance for local groups.

2. The Tanana Chiefs Conference, as the only agency which provides services throughout the Interior, is in a position to lead the way in service delivery for the handicapped, at least in the rural parts of the region. The Tanana Chiefs Conference should consider contracting with the State to provide in-home services and other support services in all the rural subregions.

3. The Arctic Alliance for People forms a basis for planning and case management in the Fairbanks area and beyond. Through the Alliance, service providers could develop meaningful strategies for working together and with service users to strengthen and expand the service delivery system.

4. There are strong trends which support development in local communities throughout the region. Doyon Limited and the Tanana Chiefs Conference (TCC) are actively investing in developing local economic and service resources. A number of communities are developing or exploring development of local education, health, and social service powers. As plans are laid for new services, there are at least two opportunities for improvement of services for the handicapped. First, some resources may become available for designated home support services. Second, other services can be designed with a focus on family and household support.

5. The region has a chance to build on local values. People express strong values of self-reliance, respect for elders, concern for child development, and desire to look after one's own family members and neighbors. Many communities have at least some positive examples of mutual aid to families with disabled members. These values may present a real challenge to the acceptability of formal home support services, but they also provide a strong foundation for support services dedicated to empowerment.

6. The lack of a centralized master plan for regional service development creates a favorable climate for innovation in home and family support. If service providers can accept responsibility for planning together, a strong, varied system might be built from the bottom up.

7. Consumer organization and participation are essential. Alaska's legislature has proven responsive to direct expressions of citizen concern for people with handicaps. In particular, parents of people with disabilities and disabled people themselves are willing to assist. If service users organize their concern for home and family support and if service providers can develop meaningful strategies for working together with service users in developing more powerful support services, it might be possible to influence State policy and appropriations.

8. Rural communities should explore the possibility of developing a new role for home and family support specialists. Community health aides have established themselves as a vital service, but their priority is, necessarily, on acute care and care for children. It would take some time for home and family support services to become established in each community, but long term care is becoming more important as communities grow. Developing new competencies for people in small villages would be a further step toward building local skills and career options.

9. All support services workers would benefit from consultation and training to expand the image of what abilities people can develop. The most effective training would come from active participation in individual planning meetings and hands-on assistance from professionals who visit homes along with workers to implement new plans. The region and the various service providers should give particular attention to provision of effective consultation and training services to village workers.

10. The Anchorage area has a personal care and attendant program which could serve as a starting point for Fairbanks. Service providers in Fairbanks should take advantage of the opportunity to examine the Anchorage program and design service options for the Central Region.

11. The Day Care Assistance Program is already organized and available in Fairbanks, Delta Junction, Fort Greely, McGrath, and Tanana. Other communities should explore this program as an avenue for providing day care services for disabled children.

12. The McGrath-Holy Cross area has received $54,000 for an infant learning program in McGrath, with itinerant services to the surrounding area. The subregion has an excellent opportunity to develop services for infants and very young children which can alleviate developmental problems at an early age.

13. The Fairbanks Rehabilitation Association's apartment program had only six participants in FY 1983, whereas it has a capacity of fourteen. This extra capacity provides an opportunity for more disabled people to pursue independent living options without increasing capital investments.

14. Specialized sitter/respite services are well established in Fairbanks for both developmentally disabled and other handicapped people.

Families involved in this Fairbanks Rehabilitation Association program are working together for these and other support services.

15. The Fairbanks Borough has demonstrated flexibility and imagination in the development of recreation services which are heavily utilized. The Borough is now developing a specialized dial-a-ride transportation system to begin the fall of 1984. Greater mobility will mean greater opportunities for people with disabilities to enjoy and contribute to community life.

CHAPTER 8

THE WESTERN REGION

Demographics

The Setting

The Western Region of Alaska, encompassing the Bethel and Wade Hampton census areas, consists of the Yukon-Kuskokwim Delta. This roughly fan-shaped area stretches 250 miles south from Norton Sound to Kuskokwim Bay and inland 200 miles to the Kuskokwim Mountains, covering 75,000 square miles. The Delta ends abruptly in the north where the Yukon River flows against the uplands of the Nulato Hills. To the south and east of the Kuskokwim River, delta lowlands merge with foothills of the Kilbuck Mountains. (Yukon Kuskokwim Health Corporation)

Lying 23 miles off the coast of the Yukon-Kuskokwim Delta, in the central Bering Sea, is 50- by 70-mile Nunivak Island, whose only village is Mekoryuk. (Ibid.)

Communities on the mainland are located along the Yukon and Kuskokwim River tributaries and around the bay. Without even the most rudimentary highway system, residents depend on boats and planes for transportation. Much of the subsistence economy and all commercial fisheries are based on water resources.

The Western Region contains 48 villages of generally less than 300 persons and the city of Bethel, a Level III community and the regional center. The Level II communities of Aniak, Hooper Bay, Mountain Village, Quinhagak, and Toksook Bay function as subregional centers. (Ibid.)

The People

The population of the Western Region was 15,590 in 1981. Alaska Natives make up over 87% of the population; the majority of these people are Eskimo who speak Yupik as a first language. On the whole, the residents are quite young, with over 49% under the age of 21. Table 8-1 depicts the population of the Western Region by age and subregion. With an average annual growth rate of 1.95%, the region is expected to grow to 16,503 people in 1984 and 17,720 by 1988, as shown in Table 8-2.

TABLE 8-1

POPULATION OF THE WESTERN REGION BY AGE AND SUBREGION, 1980

	Population by Age Groups					
Area	0-2	3-5	6-20	21-64	65+	Total
Bethel Area	804	705	3,739	5,320	431	10,999
Wade Hampton	310	379	1,747	2,051	178	4,665
TOTAL	1,114	1,084	5,486	7,371	609	15,664

Source: U.S. Department of Commerce, Bureau of the Census. 1980 Census of Population, General Population Characteristics, Part 3 Alaska. PC80-1-B3 Alaska. Washington, D.C. August, 1982. Pp. 3-56-3-57.

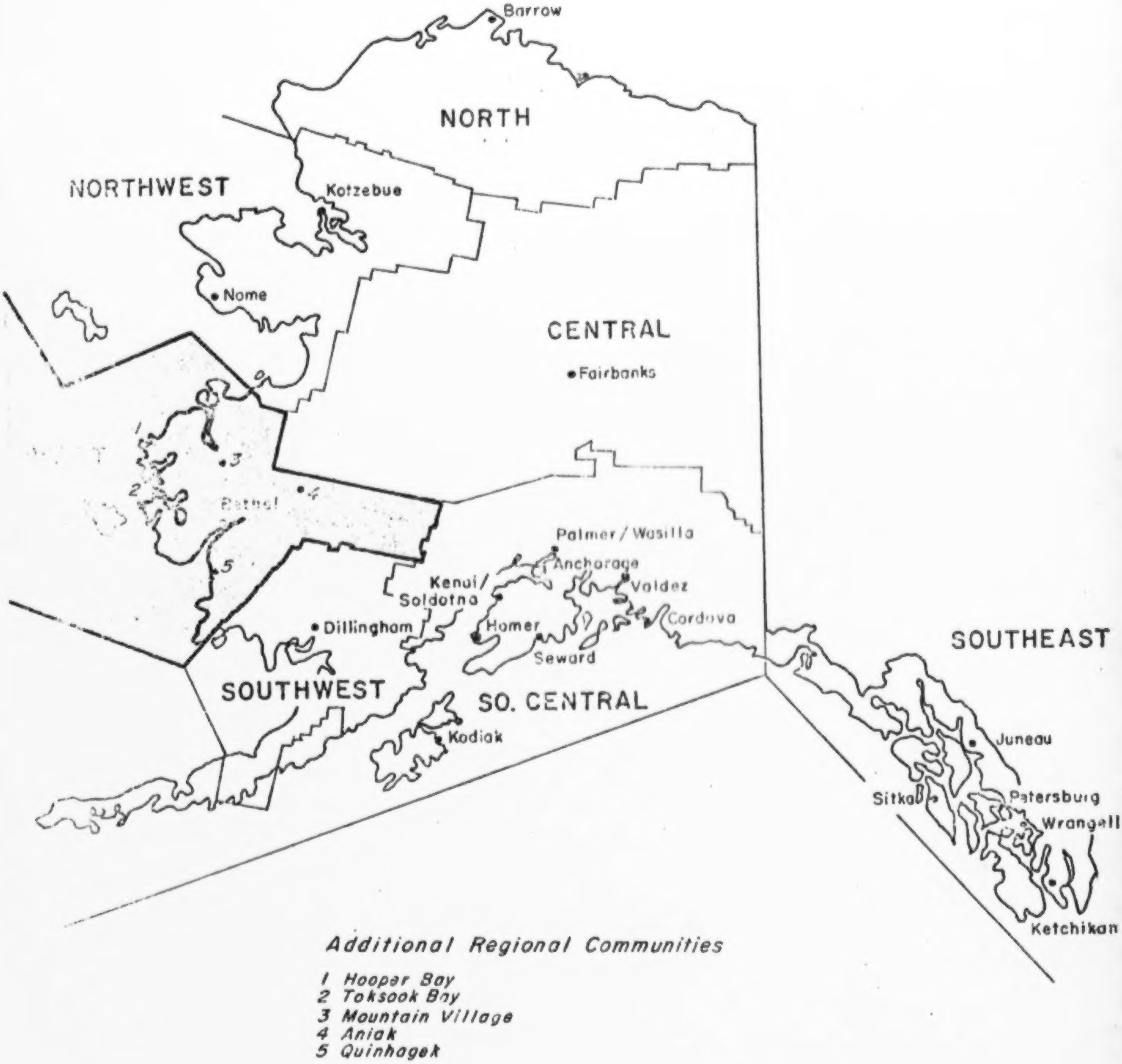
TABLE 8-2

POPULATION OF THE WESTERN REGION BY AGE GROUP, AND PROJECTED TO 1984 AND 1988

	Population by Year		
Age Group	1980	1984	1988
0-2	1,114	1,173	1,260
3-5	1,084	1,142	1,226
6-20	5,486	5,780	6,206
21-64	7,371	7,766	8,339
65+	609	642	689
TOTAL	15,664	16,503	17,720

Source: U.S. Department of Commerce, Bureau of the Census. 1980 Census of Population, General Population Characteristics, Part 3 Alaska. PC80-1-B3 Alaska. Washington, D.C. August, 1982. Pp. 3-56-3-57.

WEST REGION


Barrow
NORTH
NORTHWEST
Kotzebue
Nome
CENTRAL
Fairbanks
3
2
4
Bethel
5
Palmer / Wasilla
Anchorage
Kenai/ Soldotna
Valdez
Cordova
Dillingham
Homer
Seward
SOUTHWEST
SO. CENTRAL
Kodiak
SOUTHEAST
Juneau
Sitka
Petersburg
Wrangell
Ketchikan
Additional Regional Communities
1 Hooper Bay
2 Toksook Bay
3 Mountain Village
4 Aniak
5 Quinhagek

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The Economy and Culture

The Yukon-Kuskokwim Delta is one of the most economically impoverished areas in the United States. The per-capita income is the lowest in the nation, unemployment levels range as high as 70%; and the cost of living is one of the highest in the nation. The region has the state's greatest percentage of Natives below the poverty level - 70.7%, a significantly higher percentage than the second highest region at 46.7%. A 1978 study shows that 85.69% of the families would probably be eligible for food stamps, yet only 26% received them. (Yukon Kuskokwim Health Corporation)

Fishing is the major industry in the region, and many Natives spend their summers at fish camps or working at fish processing plants. There is some hunting and trapping in the forested upper reaches of the region. According to the 1979 Tribal Specific Health Plan of the Yukon-Kuskokwim Delta, approximately 73% of the residents regard themselves as subsistence hunters and fishermen.

The vast majority of employed persons in Bethel work in some area of public service employment. Public administration, education, hospital and health services, and welfare, religious, and non-profit organizations represent the major employment sectors.

The Tribal Specific Health Plan showed an unemployment rate of 60.79%, although estimates varied from 71.7% to 51%. Many Natives must turn to welfare and unemployment benefits to survive the long winter months.

Social Problems

The tremendous social problems of alcoholism, suicide, mental illness, domestic violence, and crime are augmented in the Western Region by widespread poverty and unemployment. The Delta area has a significantly higher infant mortality rate than the remainder of the state's Alaska Native population and 150% greater than that of the United States as a whole. Accidents, in the form of fire and poisoning, are the leading cause of death for children aged 1-4. Drownings and homicides are major killers of the 15-34 age group, while suicides are greatest among males aged 15-24. (Yukon Kuskokwim Health Corporation)

The Target Population

As described in Chapter V, all children who are substantially handicapped are considered to be developmentally disabled. Those people make up about 3% of the age groups 0-2 and 3-5 and 1.87% aged 6-20. Adults are counted among the developmentally disabled only if their impairments arose in childhood. On the average, 1.49% of the population aged 21-64 and .5% aged 65+ are developmentally disabled. In addition, about 1.90% of the people aged 21-64 and 10% aged 65+ have other substantial limitations.

Table 8-3 summarizes the number of Western Region residents with substantial disabilities. Altogether, there were approximately 282 developmentally disabled and 201 otherwise disabled people in the Western Region in 1980. By 1988, those numbers are expected to rise to 318 and 227, respectively. Around 153 will be in the school-aged (3-20) population. Table 8-4 estimates numbers of substantially disabled people by age group for 1984 and 1988.

Community Descriptions

Regional Center

Bethel, a Level III community, is the major service, transportation, and commercial center for the Western Region. As of July 1, 1981, Bethel's population was 3,549, making it the fourteenth largest town in Alaska. At that time, the community was 67.6% Native; among the Native population, the average age was 20.3 years. (Alaska Department of Labor, 1982c; U.S. Department of Commerce, Bureau of the Census)

As the regional center, Bethel maintains a modern airport which handles two flights daily to Anchorage via Wien Air Alaska. Wien also provides bush plane service from Bethel to surrounding villages. There are a number of private air taxi services available as well.

Bethel is also the headquarters for the Bethel Service Unit of the Alaska Area Native Health Service; the Bethel PHS Hospital; the public health nurses of the Alaska Department of Public Health; the Calista Native Regional Corporation; the Yukon Kuskokwim Health Corporation; and, the Lower Kuskokwim School District. The Bureau of Indian Affairs and the Alaska Division of Family and Youth Services operate regional offices in Bethel.

Level II Communities

There are five Level II communities in the Western Region which serve as subregional centers for their immediate areas.

Aniak, northeast of Bethel on the Kuskokwim River, had a 1980 population of 341, of whom 63.9% were Native. Aniak has resident behavioral health personnel and is the base station for a public health nurse who itinerates to surrounding villages. (South Central Health Planning and Development, 1982)

Hooper Bay, on Nuok Spit on the Bering Sea, had 627 residents in 1980, of whom 95.4% were Native. This population made Hooper Bay the second largest community in the Western Region. Although no itinerant services operate out of Hooper Bay, the community does offer alcoholism services on site. (Ibid.)

Mountain Village, on the Yukon River, had a 1980 population of 583, 92.5% of whom were Native. The Alaska Division of Family and Youth Services maintains a field office in Mountain Village, which is also the headquarters for the Lower Yukon School District. Mountain Village has resident alcoholism and drug abuse services as well. (Yukon Kuskokwim Health Corporation)

TABLE 8-3

WESTERN REGION ESTIMATED POPULATION OF PERSONS WITH SUBSTANTIAL HANDICAPS, 1980

Age Group	Persons with Substantial Handicaps Developmentally Disabled	Other	Total
0-2	33	0	33
3-5	33	0	33
6-20	103	0	103
21-64	110	140	250
65+	3	61	64
TOTAL	282	201	483

Sources: U.S. Department of Commerce, Bureau of the Census. 1980 Census of Population, General Population Characteristics, Part 3 Alaska. PC80-1-B3 Alaska. Washington, D.C. August, 1982. Pp. 3-56-3-57.

Governor's Council for the Handicapped and Gifted. 1981-83 Alaska Developmental Disabilities State Plan. Fairbanks, Alaska. August, 1980. Pp. 25-29.

Urban Institute. Report of the Comprehensive Service Needs Study. DHEW-RSA. June, 1975. Pp. 57-58, 72.

Older Alaskans Commission. Phone interview with Lawry Robertson. January, 1983.

Methodology: See Appendix.

TABLE 8-4

ESTIMATED SUBSTANTIALLY DISABLED* POPULATION OF THE WESTERN REGION, by AGE, 1980 and PROJECTED TO 1984 and 1988

	Substantially Disabled* Population		
Age Group	1980	1984	1988
0-2	33	35	38
3-5	33	34	37
6-20	103	108	116
21-64	250	264	282
65+	64	67	72
TOTAL	483	508	545

*Includes both developmentally disabled and other disabled people.

Sources: U.S. Department of Commerce, Bureau of the Census. 1980 Census of Population, General Population Characteristics, Part 3 Alaska. PC80-1-B3 Alaska. Washington, D.C. August, 1982. Pp. 3-56-3-57.

Governor's Council for the Handicapped and Gifted. 1981-83 Alaska Developmental Disabilities State Plan. Fairbanks, Alaska. August, 1980. Pp. 25-29.

Urban Institute. Report of the Comprehensive Service Needs Study. DHEW-RSA. June, 1975. Pp. 57-58, 72.

Older Alaskans Commission. Phone interview with Lawry Robertson. January, 1983.

Methodology: See Appendix.

Quinhagak is on the Kuskokwim Bay at the mouth of the Kanektok River. The village had 412 residents in 1980, of whom 97.6% were Native. Quinhagak has resident alcoholism services. (South Central Health Planning and Development)

Toksook Bay lies on the north shore of Kangirlvar Bay off the Etolin Strait. Its 1980 population of 333 was 93.7% Native. Like Quinhagak, Toksook Bay has resident alcoholism services. (Ibid.)

Level I Communities

The Western Region contains forty Level I villages and numerous other camps which are occupied at least part of each year. These villages vary in size from Emmonak, with 567 residents, to Red Devil, with 39. (Alaska Department of Labor, 1982c)

Table 8-5 outlines village-by-village populations for the Western Region, as of 1980. Each community's level is noted.

Service Flow Patterns

Movement of people within the Western Region has traditionally followed the navigable waterways and the Bering Sea coastline. Although air travel is now usually preferred, the flow patterns remain. Level I community residents generally travel downstream to Aniak and Mountain Village for some services. The major service center and seat of itinerant programs, however, is Bethel. People from throughout the Western Region come to Bethel for hospitalization, prematernal care, alcoholism detoxification, and other services which are not available or feasible for Level I and II communities.

For specialized care not available within the Western Region, most residents travel to Anchorage.

TABLE 8-5

POPULATION OF THE WESTERN REGION BY VILLAGE, WITH COMMUNITY LEVELS, 1980

Village	Level of Community	Population
Aniak	I	341
Akiachak	I	438
Akiak	I	198
Akolmiut	I	641
Alakanuk	I	522
Atmautluak	I	219
Bethel	III	3,576
Cape Newenham	I	43
Chefornak	I	230
Chevak	I	466
Chuathbaluk	I	105
Crooked Creek	I	108
Eek	I	228
Emmonak	I	567
Goodnews Bay	I	168
Hooper Bay	II	627
Kalskag (Upper)	I	129
Kalskag (Lower)	I	246
Kipnuk	I	371
Kongiganak	I	239
Kotlik	I	293
Kwethluk	I	454
Kwigillingok	I	354
Lime Village	I	48
Marshall	I	262
Mekoryuk	I	160
Mountain Village	II	583
Napakiak	I	262
Napaskiak	I	244
Newtok	I	131
Nightmute	I	119
Oscarville	I	56
Pilot Station	I	325
Pitka's Point	I	88
Platinum	I	55
Quinhagak	II	412
Red Devil	I	39
Russian Mission	I	169
St. Mary's	I	382
Scammon Bay	I	250
Sheldon Point	I	103
Sleetmute	I	107
Sparrevohn Station	I	26
Stony River	I	62
Toksook Bay	II	333
Tuluksak	I	236
Tuntutuliak	I	216
Tununak	I	298
Unassigned	-	135
TOTAL		15,664

Source: Alaska Department of Labor. Alaska Population Overview 1981. Pp. 16-17.

Available Services

Health Services

Health services in the Western Region are provided by three major entities: 1) the Indian Health Service; 2) the Alaska Division of Public Health; and, 3) the Yukon Kuskokwim Health Corporation.

The Alaska Area Native Service operates the Bethel Service Unit Hospital, which includes both inpatient and outpatient programs. The facility is a 42-bed general hospital, with thirty beds for medical/surgical and pediatric patients and twelve for obstetrics. The general surgery is largely minor elective procedures. Major elective surgical patients are transferred to the Alaska Native Medical Center in Anchorage or to one of the other hospitals. Major emergency surgery is performed in Bethel only if necessary due to the emergent condition or inability to transfer to Anchorage. The outpatient clinic and emergency facility handle routine and special clinics. Support services include laboratory, x-ray, and pharmacy. Dental services are provided at the hospital, as are environmental health services, social services, and a number of cooperative programs. (Yukon Kuskokwim Health Corporation)

The public health nurses (PHNs), under jurisdiction of the Alaska Division of Public Health, provide the bulk of itinerant care to the villages. They are organized according to the district team concept. All PHNs are stationed in Bethel, with the exception of one itinerant nurse who operates out of Aniak. The PHNs visit each village three to four times a year. Multiple services are provided, including: 1) communicable disease control; 2) maternal care; 3) family planning services; 4) infant and child care; 5) school health services; 6) handicapped children's services; 7) child development services, including recognition, evaluation, and follow-up of children with developmental disabilities; 8) communicative disorders and eye care; 9) chronic disease follow-up; 10) mental health; 11) health surveillance; and, 12) community health aide training. The Bethel Health Center is staffed by a PHN and a Native licensed public health practical nurse. The staff coordinates efforts with nurses in the elementary, middle, and high schools, the school dormitory, and the Bethel Hospital. (Ibid.)

The Yukon Kuskokwim Health Corporation employs about 120 people, including 68 community health aides located in 48 villages, and provides a wide range of health promotion, prevention, and primary health care services funded from a variety of state, federal, and private sources. These programs include: 1) dental disease prevention; 2) community liaison; 3) alcoholism treatment; 4) health education; 5) health aide services and training; 6) mental health services; 7) community health representatives; 8) streptococcal surveillance; 9) maternal and child health and family planning; 10) accident prevention; 11) emergency medical services; 12) eye care; and, 13) nutrition services. (Ibid.)

Table 8-6 presents a summary of health services in the Western Region by village.

TABLE 8-6

WESTERN REGION
HEALTH SERVICES by COMMUNITY, 1983

			Prevention				Early Identification											
Community	Level	PC	SHE	PA	WCP	I	PNT	MDS	VHS	MTS	D&E	MS	DS	OT	PT	SSH	HHN	HHA
Aniak	I	L			L	L		L	I			L	I					
Akiachak	I	L			L	L		I	I			I	I					
Akiak	I	L			L	L		I	I			I	I					
Akolmiut	I																	
Alakanuk	I	L			L	L		I	I			I	I					
Atmautluak	I	L			L	L		I	I			I	I					
Bethel	III	L			L	L	L	L	L	L	L	L	L					
Cape Newenham	I																	
Chefornak	I	L			L	L		I	I			I	I					
Chevak	I	L			L	L		I	I			I	I					
Crooked Creek	I	L			L	L		I	I			I	I					
Chuathbaluk	I	L			L	L		I	I			I	I					
Eek	I	L			L	L		I	I			I	I					
Emmonak	I	L			L	L		I	I			I	I					
Goodnews Bay	I																	
Hooper Bay	II	L			L	L		I	I			I	I					
Kalskag (Upper)	I	L			L	L		I	I			I	I					
Kalskag (Lower)	I	L			L	L		I	I			I	I					
Kipnuk	I	L			L	L		I	I			I	I					
Kongiganak	I	L			L	L		I	I			I	I					
Kotlik	I	L			L	L		I	I			I	I					
Kwethluk	I	L			L	L		I	I			I	I					
Kwigillingok	I	L			L	L		I	I			I	I					
Lime Village	I	L			L	L		I	I			I	I					
Marshall	I	L			L	L		I	I			I	I					
Mekoryuk	I	L			L	L												
Mountain Village	II	L			L	L		I	I			I	I					
Napakiak	I	L			L	L		I	I			I	I					
Napaskiak	I	L			L	L		I	I			I	I					
Newtok	I	L			L	L		I	I			I	I					
Nightmute	I	L			L	L		I	I			I	I					
Oscarville	I	L			L	L												
Pilot Station	I	L			L	L		I	I			I	I					
Pitka's Point	I	L			L	L		I	I			I	I					
Platinum	I																	
Quinhagak	II	L			L	L		I	I			I	I					
Red Devil	I	L			L	L		I	I			I	I					
Russian Mission	I	L			L	L		I	I			I	I					
St. Mary's	I	L			L	L		I	I			I	I					
Scammon Bay	I	L			L	L												
Sheldon Point	I	L			L	L		I	I			I	I					
Sleetmute	I	L			L	L		I	I			I	I					
Sparrevohn Station	I																	
Stony River	I	L			L	L		I	I			I	I					
Toksook Bay	II	L			L	L		I	I			I	I					
Tuluksak	I	L			L	L		I	I			I	I					
Tuntutuliak	I	L			L	L		I	I			I	I					
Tununak	I	L			L	L		I	I			I	I					

I = itinerant
PC = Prenatal care
SHE = School health education
PA = Public awareness
WCP = Well-child program
I = Immunizations
PNT = Prenatal Testing

L = locally-based
MDS = Medical/developmental screening
VHS = Vision and hearing screening
MTS = Metabolic screening
D&E = Diagnosis and evaluation of handicapping conditions
MS = Medical services

DS = Dental services
OT = Occupational therapy
PT = Physical therapy
SSH = Speech and hearing services
HHN = Home health nursing
HHA = Home health aide services

Sources: South Central Health Planning and Development. Health Systems Plan 1982-1986. Anchorage, Alaska. 1982. Yukon Kuskokwim Health Corporation. Tribal Specific Health Plan, Yukon-Kuskokwim Delta. Don Bantz and Associates. Anchorage, Alaska. 1979.

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Support Services

Support services are those services which are needed in addition to adequate medical care, educational and vocational services, and employment opportunities in order for a substantially handicapped person to live independently or with his/her family. There are three major types of support services-maintenance services, living skills training services, and material support services.

Table 8-7 summarizes the support services available in the Western Region.

Maintenance Services

Day care services are provided in Aniak and Bethel through licensed programs and also through informal sitter arrangements. The Alaska Department of Community and Regional Affairs operates the Day Care Assistance Program to help economically stressed families to offset the high cost of child care in these two communities. The program supplemented child care payments for 105 families in Aniak and Bethel in FY 1983, for a total cost of $109,122. The average cost per child was $1,039. There were no substantially disabled children among the clientele, although the program is available to them if their parents meet the eligibility guidelines. Outside of Bethel and Aniak, any sitter services provided are on an informal basis.

In addition to generic day care services, an estimated twenty families in the Western Region need respite care/specialized sitter services for their substantially disabled members. At this time, these services are unavailable.

Homemaker services provide household assistance, chore service, and/or non-medical personal assistance to enable a person and his/her family to live at home. The Alaska Division of Family and Youth Services contracts with Alaska Management Technologies to provide homemaker services statewide. However, services are not currently offered in many communities. Homemaker services are available in Bethel, Hooper Bay, Quinhagek, Mountain Village, and seventeen Level I communities. Services were provided to 58 substantially handicapped people at a total cost of $97,788, or $1,686 per client. The average hours of service per client was 138.2.

Home health aide support is a special resource made available to individuals who need health-related personal care in order to maintain an independent, community-based living arrangement. Home health aide services were provided to four clients in Bethel through the Alaska Division of Public Health in FY 1983. The cost per client was $1,725, for a total of $6,900. No other communities in the Western Region had home health aide, home nursing, or personal aide/attendant services.

Specialized transportation services for the handicapped are not available in the Western Region except as provided through the school districts and senior citizen programs.

Bautista House in Bethel runs recreation programs designed specifically for the handicapped, with an activity center which includes physical fitness programs and hobbies/crafts. The Special Olympics program is also available in some communities.

Developmental Services

Developmental services are offered in conjunction with the Bautista House program, which provides in-home training and community support in the villages. Bautista House's staff also provide family counseling and training. The Community Mental Health program services are available to people with disabilities and their families for evaluation, counseling, and mental health services. The only other developmental services available in the region are those provided through the schools and informally through community health aides, itinerant public health nurses, and other individuals.

Material Support Services

Cash assistance is available to eligible individuals and families in the Western Region on the same basis as elsewhere in the state. The major categories of special assistance to the handicapped are Aid to the Disabled and Aid to the Blind, through the Alaska Division of Public Assistance, and Supplemental Security Income (SSI) payments, in accordance with the federal Social Security Act.

Personal adaptive equipment is provided to disabled children through Alaska's Handicapped Children's Program. Personal adaptive equipment for adults and environmental adaptive equipment for people of all ages are generally unavailable except through private or third-party payment or on an informal basis.

Residential Services

Services Available in the Western Region

About 95% of the disabled people in the Western Region live in their own homes and the natural environment. The other five percent seek residential services in augmented or devised placements within the region or go outside of the region for care.

Residential services which are available within the Western Region include augmented environments and one type of devised environment. All of the people who used these services during FY 1983 were residents of the Western Region prior to their participation in an augmented or devised program.

The Alaska Division of Family and Youth Services (DFYS) offers subsidized adoptions to enable adoptive placement of children who require medical or other services beyond the financial means of their adoptive families. During FY 1983, there was one child in the Western Region who was in a subsidized adoptive placement, which is considered an augmented environment.

TABLE 8-7

SUPPORT SERVICES AVAILABLE IN THE WESTERN REGION, FY 1983

Type of Service	Availability*	Substantially Handicapped Clients Served	Average Cost Per Client	Total Costs for Handicapped Clients
MAINTENANCE SERVICES				
Day care/sitter	P	NR	NR	NR
Day care assistance program	P	NR	$1,039	NR
Respite/specialized sitter	U	--	--	--
Homemaker	P	58	$1,686	$97,788
Home health aide	P	NR	$1,725	NR
Home health nursing	U	--	--	--
Personal aides and attendants	U	--	--	--
Transportation	S	NR	NR	NR
Recreation	P	NR	NR	NR
LIVING SKILLS TRAINING SERVICES	P	NR	NR	NR
MATERIAL SUPPORT				
Financial assistance	A	NR	NR	NR
Environmental adaptive equipment	U	--	--	--
Personal adaptive equipment	U	--	--	--

* A = available; P = available in only some parts of the region; U = unavailable; S = through the schools.

Sources: Alaska Department of Community and Regional Affairs, Division of Employment Opportunity. Day Care Assistance Programs Mid Year Summary, FY 1983. Juneau, Alaska. February, 1983.

Alaska Department of Community and Regional Affairs, Division of Employment Opportunity. Unpublished data concerning the day care assistance grant program, FY 1983. Juneau, Alaska. March, 1983.

Alaska Department of Health and Social Services, Division of Family and Youth Services. Computer print-out on homemaker services program utilization. Juneau, Alaska. December, 1982.

Alaska Department of Health and Social Services, Division of Public Health, Section of Nursing. Home Health Aide Services, FY 1983. Juneau, Alaska. May 17, 1983.

Alaska Management Technologies. Correspondence with the Governor's Council for the Handicapped and Gifted concerning homemaker services program utilization. Juneau, Alaska. January, 1983.

Bethel Social Services, Inc. Developmental Disabilities Program Proposal for FY 1983. Submitted to the Alaska Division of Mental Health and Developmental Disabilities. Bethel, Alaska. July, 1982.

The DFYS also provides foster care for substantially disabled children and youth in the Western Region. During FY 1983, one such child was in foster care in this region. His foster home is considered an augmented environment.

The only devised environment designed for handicapped people in the Western Region is the Bautista House Boarding Home in Bethel. This facility provides residential services for nine adults aged 21-64.

Facilities Utilized by Residents of the Western Region

During FY 1983, nine individuals who consider the Western Region to be their home lived in augmented environments. Two of them, as mentioned above, were in either subsidized adoptive or foster homes within the Western Region under jurisdiction of the Alaska Division of Family and Youth Services. Three children, one aged 0-5 and two aged 6-20, participated in the ARMSI-Satellite Home Program in Anchorage. Four adults aged 21-64 took part in the Hope Cottages Independent Living Program, also in Anchorage.

During this same time period, fifteen Western Region residents lived in devised environments. Besides the nine people in the Bautista House Boarding Home in Bethel, six individuals were placed in Anchorage. Two school-aged children lived in Hope Cottages Children's Group Homes. One youth and three adults resided in Hope Cottages Adult Group Homes.

Protective residential services are unavailable in the Western Region, so the Western Region residents in need of such care had to leave the region. One adult lived in the Nakoyia Health Care Center in Anchorage. Two adults were in the Wesleyan Nursing Home in Seward. Two youth aged 6-20 and five adults aged 21-64 were placed in the Harborview Developmental Center in Valdez. Finally, one child aged 0-5 and five older children lived in the Hope Cottages ICF-MR facility in Anchorage.

Table 8-8 outlines all of the residential placements of residents of the Western Region during FY 1983.

Residential Service Needs of Western Region Residents

In the Western Region, as Table 8-9 shows, approximately seventeen people were estimated to need some form of residential assistance in 1983. A total of forty people received residential services. Eleven people received such care in their home region. As with the other regions, there is some discrepancy between numbers needing service and numbers receiving it, especially in the age group 21-64. There are three times as many people in protective environments (16) as projection methods and provider surveys indicate is appropriate (5).

There are several possible explanations for the relatively large numbers of people in protective environments, including random chance. However, one likely explanation for at least some of the people is that they were placed in nursing homes and institutions because of a lack of services in their home communities, especially in years past. Past residential and educational services analyses have shown a relatively higher number of Western Region people with disabilities have been identified as disabled and placed away from their homes and the region for care. Some studies have reported high relative numbers of dependent children placed out-of-region as well. It will be important to analyze rates of placements over the past five years and to examine co-relations with availability of other services such as infant learning, special education, and vocational opportunities.

Cost of Residential Services Provided in the Western Region

Augmented environment programs are generally the least costly form of residential service. In the Western Region, subsidized adoption averages $9.86 per day, for a total FY 1983 cost of $3,600. Foster care is second in cost, at $18.90 per client day, for a total FY 1983 expenditure by the State of $6,899 in the Western Region.

The only devised environmental service in the Western Region is the Bautista House Boarding Home. Rates there averaged $29.00 per client day, for a total FY 1983 expenditure of $95,265.

Table 8-10 summarizes the financial aspects of residential care in the Western Region.

Education Services

Infant Learning Program

Bethel Social Services, Inc. sponsors the PATCH Infant Learning Program which serves Bethel and the Western Region's Yukon Kuskokwim Delta. PATCH is the result of a "concerted effort of those Bethel agency personnel responsible for the health, welfare, and education of handicapped children to work closely together and provide more effective services". This description in the Infant Learning Program F84 grant proposal goes on to describe the Infant Learning Program as unique in two ways:

1. It is the only program available for handicapped infants and their parents that goes beyond diagnosis of a problem, and
2. It functions within a network of agencies toward the goals of cooperation and communication. This network is called PATCH, the Professional Assistance Team for the Chronically Handicapped.

Needs for infant learning services are great in the Western Region because the incidence of otitis media and H-flu meningitis are among the highest in the United States. Otitis media affects about 20% of the very young children in the region and is correlated with early difficulties in learning through auditory channels. Almost all cases of H-flu meningitis are children under age three. Other medical factors of high incidence in the region include pneumonia and viral infectious, tuberculosis, hepatitis, and a failure to thrive syndrome.

TABLE 8-8

RESIDENTIAL PLACEMENTS OF WESTERN REGION RESIDENTS WITH SUBSTANTIAL HANDICAPS, FY 1983

Program by Type of Environment	Location	Number of Residents by Age Group				
		0-5	6-20	21-64	65+	Total
AUGMENTED						
ARMSI Satellite Home Program	Anchorage	1	2	0	0	3
Hope Cottages Independent Living Program	Anchorage	0	0	4	0	4
DFYS Subsidized Adoption	W Region	0	1	0	0	1
DFYS Foster Care	W Region	0	1	0	0	1
DEVISED						
Hope Cottages Children's Group Homes	Anchorage	0	2	0	0	2
Hope Cottages Adult Group Homes	Anchorage	0	1	3	0	4
Bautista House Boarding Home	Bethel	0	0	9	0	9
PROTECTIVE						
Harborview Developmental Center	Valdez	0	2	5	0	7
Hope Cottages ICF-MR	Anchorage	1	5	0	0	6
Nakoyia Health Care Center	Anchorage	0	0	1	0	1
Wesleyan Nursing Home	Seward	0	0	2	0	2
TOTAL		2	14	24	0	40

Source: Governor's Council for the Handicapped and Gifted. Survey of Provider Agencies, January - June, 1983. Fairbanks, Alaska. July, 1983.

TABLE 8-9

NUMBERS OF SUBSTANTIALLY HANDICAPPED PERSONS NEEDING AND RECEIVING RESIDENTIAL PLACEMENTS, WESTERN REGION, 1983

	Number of People				
Placement by Age Group	Needing Service	Receiving Service in Home Region	Receiving Service Outside Home Region	Unserved	Unserved in Home Region
AUGMENTED ENVIRONMENT					
0-5	1	0	1	0	1
6-20	2	2	2	0	0
21+	3	0	4	0	3
All ages	6	2	7	0	4
DEVISED ENVIRONMENT					
0-5	1	0	0	1	1
6-20	2	0	3	0	2
21+	3	9	3	0	0
All ages	6	9	6	1	3
PROTECTIVE ENVIRONMENT					
0-5	1	0	1	0	1
6-20	1	0	7	[6]	1
21+	3	0	8	0[5]	3
All ages	5	0	16	0[11]	5
TOTAL	17	11	29*	[10]	12

* = It appears that more people are receiving protective residential services than estimates warrant. Discrepancies may be due to a number of factors discussed in the plan narrataive.

[] = People "over-served" in protective settings who may be inappropriately placed.

Source: Governor's Council for the Handicapped and Gifted, FY 81-82 DD State Plan, Fairbanks, Alaska. Chapter 6.
Surveys of provider agencies. January, 1983.
Analysis of special education and residential placement data. June, 1983.

Methodology: Estimates of place of residence for substantially handicapped people are: 95% natural, 2% augmented, 1.7% devised, and 1.3% protective.

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TABLE 8-10

COSTS AND FUNDING SOURCES FOR RESIDENTIAL SERVICES PROVIDED IN THE WESTERN REGION, FY 1983

Facility/Program	Funding Source	FY 1983 Budget for Services to Persons with Substantial Handicaps	Average Daily Cost Per Handicapped Resident
AUGMENTED			
DFYS Foster Care	State General Fund	$6,899	$18.90
DFYS Subsidized Adoptions	State General Fund	3,600	9.86
AUGMENTED, Subtotal	All Sources	10,499	28.76
DEVISED			
Bautista House Boarding Home	State General Fund	95,265	29.00
GRAND TOTAL, ALL SETTINGS		$105,764	$57.76

Sources: Governor's Council for the Handicapped and Gifted. Survey of Provider Agencies, January - June, 1983. Fairbanks, Alaska. July, 1983.
Alaska Department of Health and Social Services, Division of Public Assistance. Monthly Nursing Home Census and Per Diem Rates. Juneau, Alaska. 1983.

Referrals of children for screening are at about 5% of the 0-3 age population. Forty-three children in twenty villages were enrolled in PATCH ILP in F82.

> "Without the program I would have been totally lost as to what I should and can do for my child. The infant learning program helped my family first adjust to the fact that we have a handicapped child. It was a great source of comfort to know that others cared and had been through the same things I was going through. It helped us contact the right organizations for information and help." (PATCH ILP Parent, 1983.)

In addition to the direct services of regular visits to the families and children in their homes to provide one-to-one training, counseling and specialized services, ILP staff are actively involved in public awareness, training, screening, and referring handicapped children to the Lower Kuskokwim School District for services.

The special education director states that ILP cooperation as a referral service has made continual delivery of services to handicapped children an easy task to accomplish. The well developed medical records on the children speed-up and facilitate the school's evaluation process so services can be started without delay.

PATCH ILP wants to be able to serve all 54 villages in the Yukon Kuskokwim region. To date about twenty plus Bethel can be served at the $153,000 funding level from the Division of Public Health. The program will employ a teacher coordinator, two full-time teacher equivalents, and five part-time village aides in F84. This will be the first year that village aides will be employed to provide the infant learning services in this region.

TABLE 8-11

WESTERN REGION
INFANT LEARNING PROGRAM ENROLLMENT STATISTICS, FY 1982

		Total Pop. 0-2	Disabled Children						ILP Utilization		Funding (in thousands)		
Community	Agency	FY80	At Risk	DD	Screened Svd	Enrolled	T	MDE	Contact Hours	Number Home Visits	FY82	FY83	FY84
Bethel	Bethel Social Services	1,114	55	33	69	43	14	35	1,071	342	153.6	126.7	153.1

Sources: Division of Public Health, Infant Learning Program Year-End Report, FY82, Anchorage. September, 1982.
Division of Public Health, FY84 budget allocations, Infant Learning Program Coordinator, Anchorage. August, 1983.

Pre-School

Head Start programs in 12 villages served 251 children in F83. Nineteen children were handicapped, sixteen with speech/language difficulties, two with mental retardation, and one physically disabled. Programs ranged from a low of eleven children to a high of twenty-seven in Bethel. F83 program costs, funded through local, state, Ruralcap, and federal IMPD monies, totalled $767,000.

Teachers and aides received training, resource materials, and coordination services through the state's Head Start Resource Access Project (RAP) operated out of Anchorage by the Easter Seal Society of Alaska. Opportunities to obtain Child Development Associate degrees for early childhood educators and day care workers are also provided through this resource project.

The four school districts in the region provide pre-school special education services. Actual numbers of students enrolled were not available. Based on total enrollments of 566 students it is estimated that thirty to fifty handicapped children received pre-school services.

BIA does not provide pre-school services. Three of the ten communities served by BIA had Head Start Programs. This left seven villages without services and an estimated fifteen children unserved.

Special Education

School enrollment and numbers of special education students in the Western Region are shown in Table 8-12.

One-half of the region's students were served by Lower Kuskokwim REAA. One-fourth or 1,400 were served by Lower Yukon REAA. The remaining one-fourth were served by Kuspuk REAA, St. Mary's school district and the BIA schools in ten communities.

As indicated earlier the size of the Western Region, the great number of small communities, climate, and traditional subsistence lifestyles combine to make provision of special education services a costly and complicated enterprise.

Many students are served by itinerant program specialists from Bethel, Mountain Village, or Aniak with additional assistance from Alaska Resources (ARMSI) or private consultants out of Anchorage. ARMSI serves thirty-four students in the region, fourteen of whom are deaf, and twelve of whom are multi-handicapped.

Seventeen Western Region children are living in Anchorage and receiving special education services as follows:

12	Anchorage Multi-handicapped Program
2	McLaughlin Youth Facility
3	State School for the Deaf

TABLE 8-12

1982-83 SPECIAL EDUCATION ENROLLMENT INFORMATION
WESTERN REGION

School District	Number of Schools	Total Enroll-ment	Number of Sp Ed Students	% of Total Enroll-ment	Exceptionality											
					MR	HH	D	SI	VH	SED	OI	OHI	SLD	DB	MH	Out of District
LEAs																
St. Mary's	2	130	37	28	4			2		6			25			
REAAs																
Kuspuk	9	329	41	13	5			1	1				34			2
Lower Kuskokwim	27	2,457	330	13	33	10	3	26		26	5	3	224			6
Lower Yukon	12	1,400	158	11	28	1	2	18	1	5			97		6	9
BIAs																
Akiachak		97	10	10	2								7		1	
Akiak		15	2	13	1								1			
Chefornak		63	8	13									8			
Chevak		165	22	13									22			
Kasigluk		36	3	8				1					2			
Kipnuk		72	14	19	2	1		1					10			
Newtok		41	7	17		4		3								
Nunapitch		71	7	10				3					4			
Toksook Bay		69	4	6	1								3			
Tuluksak		63	12	19	1					1			10			
TOTAL		5,008	655**	13	77	16	5	55	2	38	5	3	447	0	7	17

** Does not include student served out-of-district.

MR = Mentally Retarded, Etc.
HH = Hard of Hearing
D = Deaf
SI = Speech Impaired
VH = Visually Handicapped
SEC = Seriously Emotionally Disturbed
OI = Orthopedically Impaired
OHI = Other Health Impaired
SLD = Specific Learning Disability
DB = Deaf/Blind
MH = Multiply Handicapped

Sources: Alaska Department of Education. 1982-83 School Year, P.L. 94-142 Count. Juneau, Alaska. December, 1982.
Alaska Department of Education. 1982-83 School Year, P.L. 89-313 Count. Juneau, Alaska. October, 1982.
U.S. Department of the Interior, Bureau of Indian Affairs, Anchorage Office. Data Search. Anchorage, Alaska. May, 1983.

TABLE 8-13

1982-83 SCHOOL YEAR FUNDING FOR SPECIAL EDUCATION PUBLIC SCHOOLS
WESTERN REGION

	FY83 Funding Sources					
	Foundation Funding					
School District	Reg. Ed. Allotment	Special Ed. Allotment	Total	P.L. 94-142 Funding	P.L. 89-313 Funding	Total Funding
LEAs						
St. Mary's	443,830	263,188	707,018	6,384		713,402
REAAs						
Kuspuk	577,506	197,391	774,897		28,413	803,310
Lower Kuskokwim	3,000,549	1,842,316	4,842,865		228,690	5,071,555
Lower Yukon	1,215,470	789,564	2,005,034		109,494	2,114,528
TOTAL	5,237,355	3,092,459	8,329,814	6,384	366,597	8,702,795

Sources: Alaska Department of Education, Division of Education Program Support, F83 P.L. 94-142 and P.L. 89-313 Distribution Calculations. Unpublished data. January, 1983.
Alaska Department of Education, Division of Management, Law, and Finance. Public School Foundation Program Calculations. March 2, 1983.

TABLE 8-14

1982-83 SCHOOL YEAR FUNDING FOR SPECIAL EDUCATION PUBLIC SCHOOLS AND BIA SCHOOLS WESTERN REGION

	FY83 Funding Sources					
	Funding					
Schools	3017 Funds	3101 Funds	Total	P.L. 94-142 Funding	P.L. 89-313 Funding	Total Funding
BIAs						
Akiachak	12,696	21,000	33,696			
Akiak	29,615	2,000	31,615			
Chefornak	8,638	6,156	14,794			
Chevak	29,411	22,298	51,739			
Kasiqhik	5,272	1,220	8,440			
Kipmak	11,586	21,547	33,133			
Newtok	0	8,728	8,728			
Nunapitch	0	13,230	13,230			
Toksook Bay	20,660	12,212	32,872			
Tuluksak	21,150	20,188	41,338			
TOTAL BIA SCHOOLS	139,058	128,579	267,637			267,637
	Reg. Ed.	Special Ed.	Total			
Total LEAs	443,830	263,188	707,018	6,384		713,402
Total REAAs	4,793,525	2,829,271	5,617,762		366,597	7,989,393
TOTAL PUBLIC SCHOOLS	5,237,355	3,092,459	8,329,814	6,384	366,597	8,702,795
TOTAL PUBLIC AND BIA SCHOOLS	5,376,413	3,221,038	8,597,451	6,384	366,597	8,970,432

Sources: U.S. Department of the Interior, Bureau of Indian Affairs, Anchorage Office. Anchorage, Alaska. Data Run. June 1, 1983.

TABLE 8-15

WESTERN REGION
1982-83 SCHOOL YEAR OUT-OF-DISTRICT PLACEMENTS

	Level of Home Comm.				Age Range				Exceptionality						
Program Placement	I	II	III	IV	3-5	6-12	13-15	16-21	MR	D	SED	OI	SLD	MH	Total Placements
Kuspuk -															
Anchorage M/H Program		1						1						1	2
State School for the Deaf	1							1		1					
Lower Kuskokwim -															
Anchorage M/H Program	2		2			3	1							4	6
State School for the Deaf	1							1		1					
McLaughlin			1					1					1		
Lower Yukon -															
Anchorage M/H Program	5	2				5		2						7	9
State School for the Deaf	1							1		1					
McLaughlin		1						1					1		
TOTALS	10	4	3	0	0	8	1	8	0	3	0	0	2	12	17

MR = Mentally Retarded
OI = Orthopedically Impaired
D = Deaf
SLD = Specific Learning Disability
SED = Seriously Emotionally Disturbed
MH = Multiply Handicapped

Source: Survey of DOE-Office for Exceptional Children personnel and DOE Contract Programs - May - June, 1983.

Vocational Services

"Vocational services" is the term applied to the activities which assist a person in preparing for, securing, and maintaining employment. Some of the services are geared to school-aged children; others are more appropriate for adults. People with substantial handicaps need the same basic set of career and employment-oriented services as does the general population. The focus and intensity of services provided to people with substantial handicaps may be a bit different from those provided to the general population, but the goal of using these services remains the same-employment.

Bethel Social Services

Bethel Social Services offers pre-vocational training through which it teaches positive attitudes, work habits, and basic skills for chronically handicapped adults. In FY 1983, the program served sixteen clients in its Bautista House residential center. Bethel Social Services is also beginning home industry activities which include assembly of toys and computer covers.

Alaska Vocational Services

Alaska Vocational Services is beginning competitive work placement services in Bethel. It also provides work adjustment and on-the-job training for clients placed in Bethel by the Alaska Division of Vocational Rehabilitation.

School Districts

The school districts in the Western Region provide career and vocational education, pre-vocational training, and vocational training as components of the regular school curriculum. The numbers of approved vocational courses offered by each district in the 1982-83 school year were: Kuspuk School District-62; Lower Kuskokwim Schools-78; Lower Yukon School District-36; and, St. Mary's School-21. These services and courses are provided to all interested students and are not designed especially for the substantially handicapped.

Enabling Services

Case Management Services

Informally, case management functions are carried out by particular agencies currently providing services to a disabled person and his or her family. For families involved in the PATCH Infant Learning Program, for example, the infant learning teacher is looked to for guidance, information, and advice by the families and other agencies. The teacher may also assist, with family approval, in making referrals, planning, and obtaining, other needed services. Community health aides are the local, resident village health professionals who also serve this function for many, also on an informal basis as an adjunct to health care responsibilities. Division of Family and Youth Services social workers and Yukon Kuskokwim Health Corporation workers also assist in case management as part of their provision of protective or other family services.

There is no formal case management "system" for people with disabilities, just as there is no such system for the general population or for other population sub-groups. For most services to be provided, however, there are requirements for individual case service planning, development of habilitation, rehabilitation, special education, or family service plans, which is the primary responsibility of the providing agency in consultation and coordination with other related service or health personnel.

Guardianship Services

Guardianship and conservatorship services for people who are disabled can only be provided for legally after following a process of filing a petition and having a hearing in Superior Court. Since guardianship, responsibility for the person and decisions for the person, and conservatorship, management of the person's finances, mean that some or all of the disabled or incapacitated person's legal rights are taken away, special legal proceedings must take place to make sure that rights are not taken away without due process and without basis.

The Fourth Judicial District includes the Bethel area. A Superior Court Judge is at Bethel and petitions may be filed and heard there. State law provides that a visitor must be appointed to investigate the situation of the person for whom a guardian is sought, to see if guardianship is necessary to protect the individual, and to identify people who might serve as guardian. If the Court determines that guardianship is necessary and that there is no relative or friend to be guardian, the Court can assign the Public Guardian to handle the person's affairs.

Staff Training and Manpower Development Services

Each agency has responsibility to provide for staff training. P.L. 94-142 requires training of teachers and other special education personnel. Title VI-B funds are provided to the school district based on special education enrollment and are utilized for training as well as child find activities. The special education outreach program, ARMSI, provides training to local people on an itinerant basis. The Division of Family and Youth Services has a training center in Anchorage for social workers employed by the Division. The Division of Public Health provides health education and training and sets aside money for annual training of infant learning program teachers. The Council has conducted surveys of individual services and included information on manpower development needs. Identified needs have been brought to the attention of the providers and to state funding agencies.

Information and Referral

In the Western Region information about services and referral to services takes place informally and formally. Because of the small number of people living in villages and in Bethel word gets around fast about new services, new workers, and about people's impressions and perceptions of service delivery. Each service provider has a portion of the over-all responsibility to explain services, answer questions, make referrals, and coordinate with other workers and people in the community. A great deal of coordination is required because of the use of itinerant services. This means that local people must plan and coordinate schedules, trips, flights, and meetings between people in the villages such as the health aides as well as with itinerant providers who may be coming from Anchorage or beyond. At this point in time there is no over-all coordination of health and social services information and referral.

Protection and Advocacy Services

Protective services are provided by the Division of Family and Youth Services. Legal services are available on a resident basis in Bethel and on an itinerant basis to the villages by Alaska Legal Services Corporation. The state Ombudsman's Office in Anchorage accepts and investigates complaints about state agencies and provides itinerant service to Bethel.

The only agency providing specialized protection and advocacy services to remedy violations of rights or due process, and to seek redress through negotiation, administrative, and legal means, and to provide assistance to disabled individuals who cannot access services themselves, is Protection and Advocacy for the Developmentally Disabled (P.A.D.D.). An advocate in Anchorage can receive inquiries and provide services to the Northern Region on an itinerant basis.

Obstacles and Opportunities

Obstacles

Every region has characteristics of geography, economics, population size, attitudes, and values which can present challenges in human service delivery. Many of these obstacles are similar from area to area; others are unique to a particular region or village. Almost every problem can be overcome through dedication and creativity on the part of community residents. The following obstacles to service delivery for the handicapped have been identified in the Western Region.

1. The physical environment poses tremendous obstacles to region-wide service delivery in western Alaska. The wide dispersal of people, long distances, and difficult travel conditions make it important to develop support competencies at the local level.

2. The small population size of the Western Region, particularly outside of Bethel, causes the provision of most services not to be feasible. There are not enough clients to share overhead costs, nor can providers maintain their technical skills with so few people to serve.

3. Lack of services in the past contributed to inappropriate placements of some clients and no services for others. There are now people in residential placements outside of their home communities who could be returned if adequate support services were available.

4. In some cases, community residents have attitudes which work against the development of local placements for severely disabled people. Positive attitudes must precede community acceptance and action.

5. In-home services face numerous obstacles in rural areas. Funding is inadequate for homemaker services and virtually non-existent for home health services. The actual need for in-home services is not known or sufficiently documented in many villages. Training for homemakers and home health aides is poor at best, and trainers are generally unavailable. There is considerable "red tape" involved in obtaining services in many cases, and villages often lack personnel to assist clients with the paperwork. Finally, no local agency or organization has yet sought or obtained the responsibility for organization and administration of a system of in-home services for its own area.

Opportunities

The planning process enables communities to change obstacles into opportunities. Concerned service providers, clients, family members, and other interested people can work together to solve problems and implement community change.

Several opportunities in the area of services for the handicapped are now available in the Western Region:

1. State law requires the State to plan, develop, and implement a comprehensive system of services and facilities for the handicapped (A.S. 47.80.100). Therefore the State is obliged to assist the Western Region to design and implement appropriate services.

2. The Yukon Kuskokwim Health Corporation (YKHC), which provides services throughout the region, is in a position to lead the way in planning and delivery of services for the handicapped. The YKHC should consider contracting with the State to provide in-home services and other support services throughout the region.

3. The region has a chance to build on local values. People express strong values of self-reliance, respect for elders, concern for child development, and desire to look after one's own family members and neighbors. Many communities have positive examples of mutual aid to families with disabled members. These values may present a real challenge to the acceptability of formal home support services, but they also provide a strong foundation for support services dedicated to empowerment.

4. Consumer organization and participation are essential. Alaska's legislature has proven responsive to direct expressions of citizen concern for people with handicaps. In particular, parents of people with disabilities and disabled people themselves are willing to assist. If service users organize their concern for home and family support and if service providers can develop meaningful strategies for working together with service users in developing more powerful support services, it might be possible to influence State policy and

appropriations. PATCH has already demonstrated the effectiveness of this collaborative approach for case management and infant learning. PATCH can be the catalyst for services in the Western Region.

5. The Yukon Kuskokwim Health Corporation, PATCH, and local communities should explore the possibility of developing a new role for home and family support specialists. Community health aides have established themselves as a vital service, but their priority is, necessarily, on acute care and care for children. It would take some time for home and family support services to become established in each community, but long term care is becoming more important as communities grow. Developing new competencies for people in small villages would be a further step toward building local skills and career options.

6. All support services workers would benefit from consultation and training to expand the image of what abilities people can develop. The most effective training would come from active participation in individual planning meetings and hands-on assistance from professionals who visit homes along with workers to implement new plans. The region and the various service providers should give particular attention to provision of effective consultation and training services to village workers such as Infant Learning village aides. The school districts in the region, together with the out-reach services expertise of Alaska Resources (ARMSI) in Anchorage can provide important resources for on-site training.

7. The Bautista House program in Bethel has an excellent start on the provision of regionwide services for the handicapped. The PATCH system provides case management services and a locus of interagency coordination. This program has an opportunity to continue work with the villages and the Bethel area to expand activities.

8. Alaska Vocational Services, which has just begun work in the Bethel area, provides a foundation for meaningful efforts in vocational areas for disabled adults. This program should be supported and continued with assignment and eventual physical location in Bethel of a Rehabilitation Counselor from the Division of Vocational Rehabilitation in-region access to vocational services and expertise will benefit the Bethel Social Services vocational program and people with handicaps who have finished school and want training and employment.

9. Services which have residential components such as the pre-maternal home and Bautista House have been existence for some time. As experience shows that small residential options are a feasible and appropriate alternative to out-of-region placement and as more support and medical services are available in Bethel, we can expect to see other types of residences and semi-independent living programs develop.

10. Bethel Social Services opened its new 5,600 square foot Norma Jean Center for Young Children in 1982. This day care center also has facilities for training teachers of young children and the Kuskokwim Community College operates an early childhood development program there. Specialized resources for day care or respite services for

handicapped children could easily be developed by the center's staff and Board of Directors.

CHAPTER 9

THE SOUTH CENTRAL REGION

Demographics

The Setting

The mainland of South Central Alaska, with its major islands, covers 83,000 square miles. Its boundaries contain four boroughs-Kenai Peninsula, Matanuska-Susitna, the Municipality of Anchorage, and Kodiak Island; and five Native regional corporations-Ahtna, Inc.; Chugach Natives, Inc.; Cook Inlet Region, Inc.; Koniag, Inc.; and, the Aleut Native Regional Corporation.

The South Central mainland region includes areas draining into the Gulf of Alaska between Icy Bay, northwest of Yakutat, and Chignik Bay on the Alaska Peninsula. The area is characterized by rugged, mountainous terrain with important exceptions in the lowlands bordering Cook Inlet, the lower Susitna Valley, the Copper River plateau, and intermittent strips along the coast. It includes part of the Wrangell Mountains, all of the Talkeetna Mountains, the eastern and southern slopes of the Alaska Range, and the Kodiak Archipelago. (South Central Health Planning and Development, 1982)

In addition to the mainland area, the South Central Region includes the Aleutian and Pribilof Islands, which contain another 11,000 square miles of land area. The Aleutian Chain consists of approximately fifty islands extending in an arc 1,100 miles long from the southwest tip of the Alaska Peninsula. The Aleutians form the southern edge of the Bering Sea. The Pribilofs, consisting primarily of St. George and St. Paul Islands, lie 200 miles north of the Aleutians and 300 miles west of mainland Alaska. (Aleutian-Pribilof Islands Association Health Department)

For purposes of planning and service development, the South Central Region consists of six subregions:

1. The Aleutian/Pribilof subregion -- consisting of the Aleutian Chain and the Pribilof Islands.

2. The Municipality of Anchorage -- comprised of the Greater Anchorage Area Borough at the northeastern end of Cook Inlet.

3. The Kenai Peninsula subregion -- including all of the Kenai Peninsula Borough, which incorporates the western shore of Cook Inlet from Tyonek to Cape Douglas, as well as the Kenai Peninsula itself.

4. The Kodiak Island subregion -- including Kodiak Island, the Alaska Peninsula from Becharof Lake to Chignik Bay, and numerous small islands.

5. The Matanuska-Susitna subregion -- ranging from Denali National Park on the northwest, encircled by the Alaska Range on the west and north, bounded by the Kenai Peninsula and Greater

Anchorage Area Boroughs and the Chugach Mountains on the south, and the Copper River Valley on the east.

6. The Valdez-Cordova subregion -- stretching from Icy Bay around Prince William Sound, down the Kenai Peninsula to English Bay; bounded on the north by the Alaska Range, on the east by Canada and the Wrangell Mountains, and on the west by the Talkeetna Mountains; including the Copper River and Prince William Sound areas.

Forms of transportation in this vast area vary from place to place. Anchorage is the center of both communication and transportation. Anchorage International Airport is a refueling and transfer stop for Asian and European trans-polar passenger flights, as well as for Canadian and domestic carriers. Many Alaskan passenger and freight lines, including air taxi and bush services, operate out of Anchorage to points all over the state. All the communities have airstrips with varying capabilities. Anchorage is the southern terminus of the Alaska Railroad. The Parks, Glenn, Denali, Richardson, Edgerton, Seward, and Sterling Highways link the major cities of the region. Finally, water access by ship, ferry, and small boat is significant. In remote areas, wintertime travel includes snowmachines and dogsleds.

The People

The South Central Region includes the Aleutian Islands, Anchorage, Kenai Peninsula, Kodiak Island, Matanuska-Susitna (Mat-Su), and Valdez-Cordova census areas. The combined population was 253,581 in 1981. (Alaska Department of Labor, 1982) Non-Natives make up the majority of the population in the region, with only 4% of Anchorage's residents being Native. In some rural communities, however, Natives constitute over 90% of the population. The people in general are older than those elsewhere in the state, although the average age is still below that of the United States as a whole. In the South Central Region, 37.4% of the population is under the age of 21. There is subregional variation, however, with percentages under 21 ranging from a low of 36.24% in the Valdez-Cordova area to 40% in the Mat-Su Borough. Similarly, there are considerable differences within the region in the proportion of the population over age 65. For the region as a whole, 2.35% of the residents are aged 65 or older; the proportion ranges, however, from a low of 1.38% in the Aleutian/Pribilof subregion to a high of 4.10% in the Mat-Su Borough. (U.S. Department of Commerce, Bureau of the Census)

Table 9-1 depicts the population of the South Central Region by age and subregion. With an average annual growth from 1970 to 1981 of 4.34%, the region is expected to grow to 286,562 people by 1984 and 330,619 by 1988, as shown in Table 9-2. Appendix A contains population projections for 1984 and 1988 for the subregions of the South Central Region.

SOUTH CENTRAL REGION

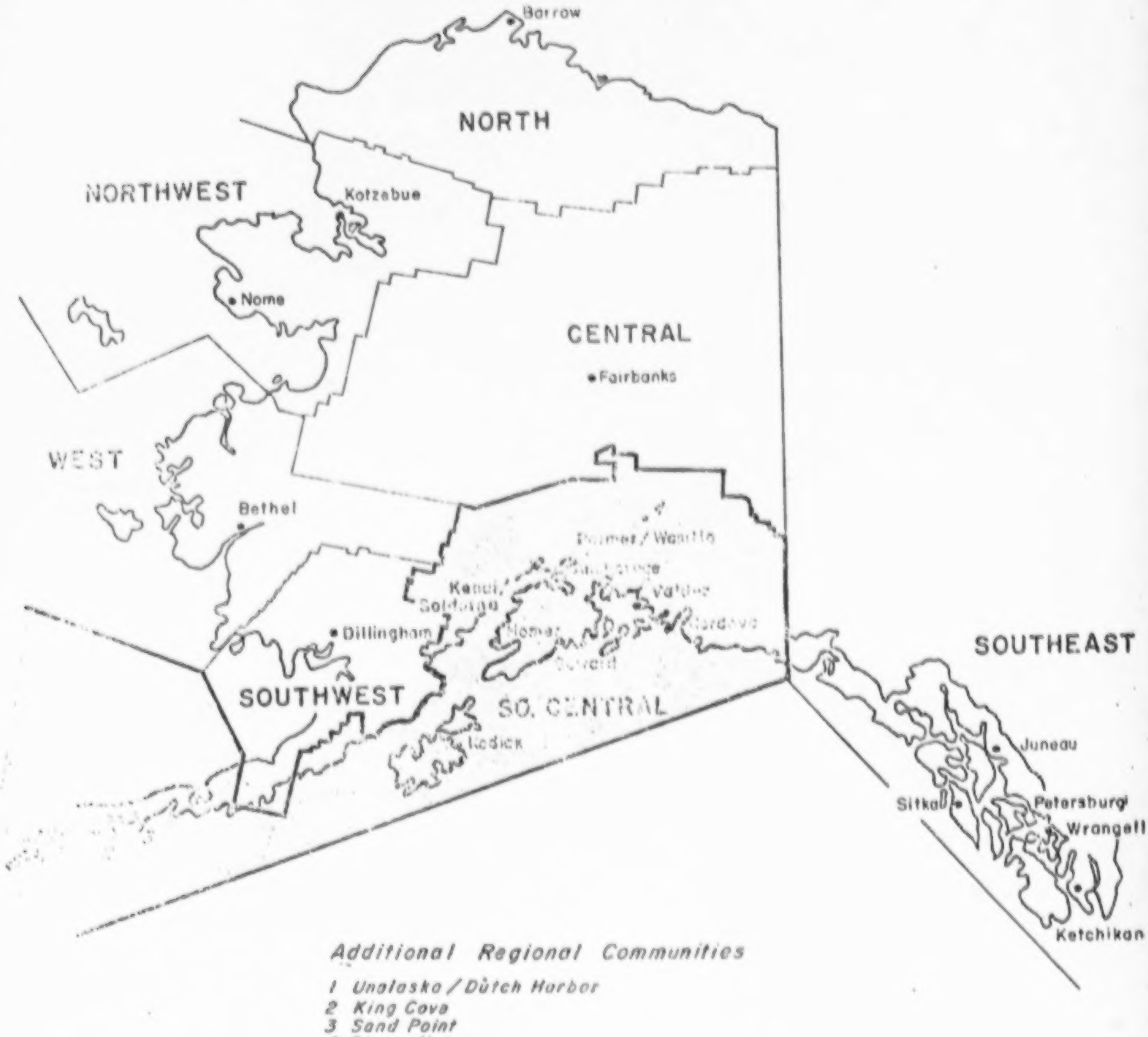
Barrow
NORTH
NORTHWEST
Kotzebue
Nome
CENTRAL
Fairbanks
WEST
Bethel
Palmer / Wasilla
Anchorage
Kenai, Soldotna
Valdez
Cordova
Dillingham
Homer
Seward
SOUTHWEST
SO. CENTRAL
Kodiak
SOUTHEAST
Juneau
Sitka
Petersburg
Wrangell
Ketchikan
Additional Regional Communities
1 Unalaska / Dutch Harbor
2 King Cove
3 Sand Point
4 Glennallen

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TABLE 9-1

POPULATION OF THE SOUTH CENTRAL REGION BY AGE AND SUBREGION, 1980

	Population by Age Group					
Area	0-2	3-5	6-20	21-64	65+	Total
Aleutian/Pribilof	401	354	2,078	4,828	107	7,768
Anchorage, Municipality of	10,356	8,975	45,523	106,057	3,520	174,431
Kenai Peninsula	1,514	1,387	6,860	14,694	827	25,282
Kodiak Island	635	523	2,519	6,007	255	9,939
Matanuska-Susitna	1,146	995	4,987	9,958	730	17,816
Valdez-Cordova	473	373	2,179	5,028	295	8,348
TOTAL	14,525	12,607	64,146	146,572	5,734	243,584

Source: U.S. Department of Commerce, Bureau of the Census. 1980 Census of Population, General Population Characteristics, Part 3 Alaska. PC80-1-B3 Alaska. Washington, D.C. August, 1982. Pp. 3-56 - 3-57.

TABLE 9-2

POPULATION OF THE CENTRAL REGION BY AGE GROUP, 1980 and PROJECTED TO 1984 and 1988

	Population by Year		
Age Group	1980	1984	1988
0-2	14,525	17,079	19,705
3-5	12,607	14,844	17,126
6-20	64,146	75,452	87,052
21-64	146,572	172,424	198,933
65+	5,734	6,734	7,770
TOTAL	243,584	286,562*	330,619*

* Totals are slightly off due to rounding.

Source: U.S. Department of Commerce. Bureau of the Census. 1980 Census of Population, General Population Characteristics, Part 3, Alaska. PC80-1-B3 Alaska. Washington, D.C. August, 1982. Pp. 3-56 - 3-57.

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The Economy and Culture

The South Central Region is an extremely diverse area, ranging from urban Anchorage, with its primarily non-Native, Western culture, to isolated villages where Native populations follow subsistence lifestyles. This dichotomy between rural and urban areas is a significant one both culturally and economically.

The growing economic divergence between Anchorage and the rest of Alaska has become so extreme as to suggest the existence of two entirely different economies. A look at nonagricultural employment and labor force data shows that Alaska's economic expansion is more specifically Anchorage economic expansion. The rest of the state is stagnating economically or showing very gradual growth. (Alaska Department of Labor, 1982a)

Urban Communities

Anchorage is the center of commerce, transportation, and communications for all of Alaska, being the major gateway between Alaska and the rest of the country. From 70% to 75% of the total tonnage of Alaska's non-petroleum cargo goes through the Port of Anchorage to be distributed throughout the state via truck, air, and rail. Over 95% of all shipments are inbound. In 1982, the Port handled 1,170,170 tons of cargo, 85% of which was not petroleum related. (Alaska Department of Labor, 1982b)

Despite all this shipping and the transportation services described earlier, all kinds of transportation, shipping, and receiving accounted for only 9.4% of total employment in Anchorage in March, 1983. The major employer, with 26.2% of the total, is government. Federal government employs 10% of the total labor force, followed by municipal (9.5%), and state government (6.7%). Wholesale and retail trade ranks second to government, with services and miscellaneous third. Construction, which is often thought of as a major source of income for Alaskans generally, accounted for only 6.6% of the total work force. (Alaska Department of Labor, 1983d)

In the Mat-Su Borough, government again ranks as the major employer, with 30.7% of the total. Services and miscellaneous (28.4%) is the second largest source of jobs, followed by wholesale and retail trade (19.3%). (Alaska Department of Labor, 1983d)

The military is also a large employer in the South Central Region. In 1980, there were 15,109 active duty personnel and 20,868 dependents in the region, the majority of whom (74.8%) lived in the Anchorage area. The major military installations are Fort Richardson and Elmendorf Air Force Base. Numerous smaller installations are scattered throughout the region. (Alaska Division of State Health Planning and Development, Northern Alaska Health Resources Association, South Central Health Planning and Development, and Southeast Alaska Health Systems Agency)

Unemployment in the Anchorage area is the lowest in the state, with 8.9% unemployed in March, 1983. (Alaska Department of Labor, 1983d)

The Gulf Coast

The main industry of the Gulf Coast is fishing and fish processing. Unemployment surged in that industry recently because 1982 was the worst fishing season of the last decade. The Kodiak and Cook Inlet areas were particularly hard hit, with major drops in the numbers of crabs and shrimp taken. This decline in catch caused a corresponding drop in fish processing employment, despite the fact that the salmon catch was above average. (Alaska Department of Labor, 1983b)

Almost all other major industry categories on the Gulf Coast grew in 1982. Much of this growth resulted from increased state spending in the form of capital projects, dividend checks, housing subsidies, subsidized business loans, an increase in area population and income, and a good tourism season. (Alaska Department of Labor, 1983b)

Valdez is the one community on the Gulf Coast which is largely immune from seasonal employment fluctuations. The single largest private-sector industry there is the transportation of oil. Unlike anywhere else in the state, transportation, communication, and public utilities employ 20-22% of the labor force, the majority of whom work at the Alyeska Pipeline terminal. Trade, construction, and other industries in Valdez have benefited as a result of this large, stable economic base for the community.

The poor fishing season and the boom in construction and tourism basically offset one another in 1982, as Valdez's economy remained stable. However, the annual unemployment rate of 13.4% was 1.3 percentage points higher than the 1981 rate. The region's rate, as always, was above the state's rate, largely because of the very seasonal nature of the economy. Cordova-McCarthy was the only division of the Gulf Coast area with a 1982 unemployment rate below double-digit figure (9.6%). The Kenai-Cook Inlet, Valdez-Chitina-Whittier, and Kodiak rates registered 15.5%, 11.4%, and 11.0% respectively. These statistics indicate that the labor market on the Gulf coast remains out of balance as more individuals seek work than there is work available. (Alaska Department of Labor, 1983b)

The Aleutian/Pribilof Subregion

Commercial fishing is an important means of employment for the civilian population of the Aleutian and Pribilof Islands, with shellfish and salmon the leading commercial crops. Government, fish processing, construction, and tourism are other sources of livelihood. The military, however, is the largest employer.

The unemployment plight of the Native civilian population in the subregion is particularly severe. An estimated 70% are without year-round jobs. (South Central Health Planning and Development, 1982)

Social Problems

The major social problems of the South Central Region are similar to those of the other regions, although many of them are less severe in the urban areas. Differences are largely in degree, not in kind. Alcohol abuse and its attendant effects dominate, with mental illness, suicide, child abuse and neglect, crime, and domestic violence all being significant causes for concern. Accidents are the leading cause of death and disability, followed by heart disease and hypertension and cancer. (South Central Health Planning and Development, 1982)

The Target Population

As described in Chapter 5, all children who are substantially handicapped are considered to be developmentally disabled. These people make up about 3% of the age groups 0-2 and 3-5 and 1.87% aged 6-20. Adults are counted among the developmentally disabled only if their impairments arose in childhood. On the average, 1.49% of the population aged 21-64 and .5% aged 65+ are developmentally disabled. In addition, about 1.90% of the people aged 21-64 and 10% aged 65+ have other substantial limitations.

Table 9-3 summarizes the number of South Central Region residents with substantial disabilities. Altogether, there were approximately 4,225 developmentally disabled and 3,358 otherwise disabled people in the South Central Region in 1980. By 1988, those numbers are expected to rise to 5,736 and 4,557, respectively. Around 2,733 will be among the school-aged (3-20) population. Tables 9-4a and 9-4b estimate the numbers of substantially disabled people by age group for each subregion.

Community Descriptions

Aleutian/Pribilof Subregion

The Aleutian/Pribilof Islands region consists of the Aleutian Islands, a chain of volcanic mountaintops stretching over 1,100 miles across the northern Pacific; a 200-mile portion of the lower Alaska Peninsula; island groups (Sanak, Shumagin, and Pavloff) off the southern coast of the Peninsula; and, the Pribilof Islands in the Bering Sea, approximately 200 miles north of the Aleutians and 300 miles west of mainland Alaska. (Aleutian-Pribilof Islands Association Health Department)

The population of this subregion was approximately 8,624 in 1981. Due to the large concentration of military personnel and dependents (64.7% of the total population), the area as a whole has a non-Native majority (70%). However, eight of the fourteen communities in the subregion are over 57% Native, and six of them are over 85% Native in population. Most of these people are of Aleut ancestry. (U.S. Department of Commerce, Bureau of the Census)

The military presence dominates the economy of the Aleutian Chain and has significant cultural impacts as well. The large military installations at Adak and Shemya also inflate the male and young adult population figures. Overall, 62.15% of the people are aged 21-64; only 1.38% are over 65. Approximately 36.47% of residents are under 21-one of the lowest proportions of children of any area of the state. Table 9-5 shows the 1980 population of the Aleutian/Pribilof subregion by community.

TABLE 9-3

SOUTH CENTRAL REGION ESTIMATED POPULATION OF PERSONS WITH SUBSTANTIAL HANDICAPS, 1980

	Persons with Substantial Handicaps*		
Age Group	Developmentally Disabled	Other	Total
0-2	435	0	435
3-5	379	0	379
6-20	1,199	0	1,199
21-64	2,183	2,785	4,968
65+	29	573	602
TOTAL	4,225	3,358	7,583

Sources:

U.S. Department of Commerce, Bureau of the Census. 1980 Census of Population, General Population Characteristics, Part 3, Alaska. PC80-1-B3 Alaska. Washington, D.C. August, 1982. Pp. 3-56 - 3-57.

Governor's Council for the Handicapped and Gifted. 1981-1983 Alaska Developmental Disabilities State Plan. Fairbanks, Alaska. August, 1980. Pp. 25-29.

Urban Institute. Report of the Comprehensive Service Needs Study. DHEW-RSA. June, 1975. Pp. 57-58, 72.

Older Alaskans Commission. Phone interview with Lawry Robertson. January, 1983.

Methodology: See Appendix.

TABLE 9-4a

ESTIMATED SUBSTANTIALLY DISABLED* POPULATION

MUNICIPALITY OF ANCHORAGE

	Substantially Disabled* Population		
Age Group	1980	1984	1988
0-2	311	360	410
3-5	269	312	356
6-20	851	986	1,124
21-64	3,594	4,162	4,745
65+	370	428	488
TOTAL	5,395	6,248	9,013

KENAI PENINSULA SUBREGION

	Substantially Disabled* Population		
Age Group	1980	1984	1988
0-2	45	55	66
3-5	42	51	60
6-20	128	157	186
21-64	97	608	726
65+	86	106	126
TOTAL	798	977	1,164

MATANUSKA-SUSITNA BOROUGH

	Substantially Disabled* Population		
Age Group	1980	1984	1988
0-2	34	56	82
3-5	30	49	71
6-20	93	153	224
21-64	485	553	810
65+	77	126	183
TOTAL	719	937	1,370

* Includes both developmentally disabled and other disabled people.

TABLE 9-4b

ESTIMATED SUBSTANTIALLY DISABLED* POPULATION

KODIAK ISLAND SUBREGION

	Substantially Disabled* Population		
Age Group	1980	1984	1988
0-2	19	20	23
3-5	16	17	19
6-20	47	50	56
21-64	204	218	242
65+	27	29	32
TOTAL	313	334	372

ALEUTIAN/PRIBILOF SUBREGION

	Substantially Disabled* Population		
Age Group	1980	1984	1988
0-2	12	14	14
3-5	11	12	13
6-20	39	44	46
21-64	165	187	193
65+	11	13	13
TOTAL	238	270	306

VALDEZ-CORDOVA SUBREGION

	Substantially Disabled* Population		
Age Group	1980	1984	1988
0-2	14	18	23
3-5	11	14	18
6-20	41	52	65
21-64	171	219	270
65+	31	40	49
TOTAL	268	343	425

* Includes both developmentally disabled and other disabled people.

With the minor exception of a few local roads, there is no highway system in the Aleutian/Pribilof area. A single commercial airline, Reeve Aleutian, and numerous small charter airlines serve the subregion. The Bureau of Indian Affairs' North Star brings cargo from Seattle to the Aleutian villages each spring, while the Pribilofs are served three times each year by the Pribilof of Alaska Marine Shipping in Seattle. The St. George Village Corporation has a plane which is leased to Peninsula Airways to provide weekly service between Cold Bay and St. George as well as regular summer flights between St. George and St. Paul.

Air access to the Aleutians is totally dependent upon weather, being subject to extremes in fog, wind, and storms which are the rule rather than the exception. All flights to villages in the Aleutians other than Cold Bay must be conducted under Visual Flight Rules and in daylight because of the lack of air navigation aids in the villages. The small number of regularly scheduled flights, coupled with a significant non-completion rate of these flights because of weather, makes access within the region quite irregular and sporadic. (Aleutian-Pribilof Islands Health Department)

Again, it is the geography and weather of the subregion which inhibit an effective, reliable communications network. Mail service is irregular and very poor. King Cove, Sand Point, and Unalaska have their own local telephone systems, but they are troubled by inclement weather, freeze-ups, lack of maintenance parts and trained personnel, and geographic barriers. Akutan, Atka, False Pass, Nelson Lagoon, Nikolski, St. George, and St. Paul each have one satellite bush phone with direct access to the Alaska Native Medical Center in Anchorage. Nikolski, False Pass, and Atka also have single sideband radios. Citizen band radios are common within the villages, providing effective links locally and with boats at sea.

Weather seems to be the overriding factor in transportation and communications in the Aleutians and Pribilofs. It also has a major impact on the health status of the people. Weather is a causal factor in the accident mortality rates and mental illness, as well as the major determinant of a person's ability to get to needed health services. (Aleutian-Pribilof Islands Association Health Department)

King Cove, Sand Point, and Unalaska are the Level II communities in the Aleutian/Pribilof subregion. Unalaska serves as the subregional center for health and social services and is the base station for National Health Services Corps physicians' assistants (the Iliuliuk Family Health Service) and the Aleutian Pribilof Islands Association Health Department. State public health nurses are stationed in Cold Bay and make itinerant visits to other communities.

Educational services in the subregion are provided by the following organizations: Adak Regional Schools, Adak; Aleutian Regional School District, Anchorage; King Cove City Schools, King Cove; Pribilof Schools, St. Paul; Sand Point School District, Sand Point; and, Unalaska City Schools, Unalaska.

Because of the weather and its resulting transportation problems and because of the general lack of services within the subregion, residents do very little traveling to the subregional center for services. Itinerants out of Cold Bay, Unalaska, and Anchorage reach most villages at some time each year. For inpatient or more sophisticated services, Aleutian/Pribilof residents travel to Anchorage.

TABLE 9-5

POPULATION OF THE ALEUTIAN/PRIBILOF SUBREGION, BY COMMUNITY WITH COMMUNITY LEVELS, 1980

Community	Level	Population
Adak Station	MR*	3,315
Akutan	I	169
Atka	I	93
Attu	I	29
Cold Bay	I	228
False Pass	I	70
King Cove	II	460
Nelson Lagoon	I	59
Nikolski	I	50
St. George	I	158
St. Paul	I	551
Sand Point	II	625
Shemya Station	MR*	600
Unalaska	II	1,322
Unassigned	-	39
SUBREGION TOTAL	-	7,768

*MR = Military reservation (no level designated).

Source: Alaska Department of Labor. Alaska Population Overview 1981. Juneau, Alaska. 1982. Pp. 16-17.

Municipality of Anchorage

It is difficult to find two areas in America which contrast more than do the Aleutian/Pribilofs and the Municipality of Anchorage. Small and remote though they are, however, the people of the Aleutian Chain and the Pribilof Islands relate directly to Anchorage for most services.

The Municipality of Anchorage, a Level IV community, is the largest population center in Alaska. In 1981, approximately 180,740 people lived in the Anchorage area, accounting for over 42% of the state's total population. Within the Municipality, 84% of the people live within the Anchorage bowl area, about 5% in the Eagle River-Chugiak area, 10% on Fort Richardson and Elmendorf Air Force Base, and a small percentage along Turnagain Arm. The population is 4% Native and 96% non-Native. Demographic characteristics such as sex and age distribution more closely resemble those of the entire nation than do corresponding characteristics of other parts of Alaska, with 60.8% of the population aged 21-64 and 37.19% aged 0-20. (South Central Health Planning and Development, 1982)

The Municipality is the major transportation, commercial, and service center for Alaska. It is a trans-shipment point for almost 75% of all goods entering the state. Anchorage International Airport is a major refueling and transfer point for air traffic in the Northern Hemisphere, as well as for many intra-state flights. The railroad and highway system radiate from Anchorage to the major urban areas of Central and South Central Alaska.

Anchorage serves as a secondary and tertiary health service center for much of the state. It is the center for the Alaska Area Native Health Service; the University of Alaska-Anchorage; the Alaska Psychiatric Institute; Alaska Pacific University; the Cook Inlet Native Association; North Pacific Rim Native Association; the Aleutian/Pribilof Islands Association; South Central Health Planning and Development; the Aleutian Region School District; Anchorage School District; and, the Southeast Regional Resource Center. Various state and federal programs provide itinerant services to rural communities throughout the state.

Kenai Peninsula Subregion

The Kenai Peninsula subregion includes all of the Kenai Peninsula south of Whittier and the western shore of Cook Inlet from Tyonek to Cape Douglas. The population is widely distributed, with concentrations along the highways. There are five large communities (1,500 - 5,000 residents), seven with populations of 300 - 1,200, and twelve smaller settlements. The 1981 population of the subregion was 26,520, with Natives constituting about 5% of the total. Approximately 38.6% of the people were younger than 21 years; 3.27% were over 65 years of age. Table 9-6 gives the 1980 population of the Kenai Peninsula subregion by community.

Although outside of this subregion, Anchorage is the area's center of communication and transportation. Airports are located in Hope, Kenai, Soldotna, Homer, Seldovia, English Bay, and Seward, and most other communities have air strips or water landing areas. The Sterling and Seward Highways and their connector roads link the major communities on the Peninsula proper. Finally, ferries run between Homer and Seldovia and also between Homer and Kodiak Island. Seward's ferry connections join Kodiak Island and various communities on Prince William Sound.

Much of the economy of the Kenai Peninsula is related to the fishing industry, particularly salmon and shellfish. Oil and tourism are also important.

TABLE 9-6

POPULATION OF THE KENAI PENINSULA SUBREGION, BY COMMUNITY, WITH COMMUNITY LEVELS, 1980

Community	Level	Population
Anchor Point	A*	226
Clam Gulch	A	50
Cooper Landing	A	116
English Bay	I	124
Fritz Creek		302
Halibut Cove	A	47
Homer	III	2,209
Hope	I	103
Jakolof Bay	I	36
Kachemak	A	403
Kalifonsky	A	92
Kasilof	A	201
Kenai	III	4,324
Moose Pass	A	76
Nikishka	A	1,109
Nikolaevsk	A	500
Ninilchik	I	341
Port Graham	I	161
Portlock	I	31
Salamatof	A	334
Seldovia	II	479
Seward	III	1,843
Soldotna	III	2,320
Sterling	A	919
Tyonek	I	239
Unassigned	-	8,047
SUBREGION TOTAL	-	25,282

*A = Adjacent community. An adjacent community is one which is clustered with a larger community for purposes of planning and service development. See Table 9-7 for a listing of clusters in the Kenai Peninsula subregion.

Source: Alaska Department of Labor. Alaska Population Overview 1981. Juneau, Alaska. 1982. P. 16.

TABLE 9-7

COMMUNITY CLUSTERS IN THE KENAI PENINSULA SUBREGION

Communities	Level
Homer cluster	
Anchor Point	A*
Fritz Creek	A
Homer	III
Kachemak	A
Nikolaevsk	A
Kenai cluster	
Kenai	III
Nikishka	A
Salamatof	A
Seldovia cluster	
Halibut Cove	A
Seldovia	II
Seward cluster	
Moose Pass	A
Seward	III
Soldotna cluster	
Clam Gulch	A
Cooper Landing	A
Kalifonsky	A
Kasilof	A
Soldotna	III
Sterling	A
Non-clustered	
English Bay	I
Hope	I
Jakolof Bay	I
Ninilchik	I
Port Graham	I
Portlock	I
Tyonek	I

A* = Adjacent community.

Source: South Central Health Planning and Development. Health Systems Plan 1982-1986. Anchorage, Alaska. 1982. Pp. 139 - 145.

Because most of the Kenai Peninsula communities are linked by roads and because the distances, though long, are not extreme, planners in the subregion have developed a "clustering concept." By this method, communities in close proximity are considered together for purposes of planning for service development. Towns and villages which are considered to be closely tied with larger, subregional centers are called "adjacent" communities. Table 9-7 describes the service clusters for the Kenai Peninsula.

Kodiak Island Subregion

The Kodiak Island subregion is comprised of Kodiak and Afognak Islands, the Alaska Peninsula from Becharof Lake to Chignik Bay, and several nearby islands. Altogether, the subregion encompasses 7,296 square miles. (Kodiak Island Borough Health Resources Council)

The population of this subregion was approximately 9,728 in 1981. The city of Kodiak and the surrounding area had about 4,678 residents, or around 48.1% of the total population. The rest of the subregion's inhabitants live in six other relatively isolated communities or scattered in single dwellings and small, unofficial villages. Approximately 25% of the population is Native; another 34% are military and dependents connected with the Kodiak Naval Station. Almost 57% of the people are aged 0-20; 2.57% are over 65. (Alaska Department of Labor, 1982c) Table 9-8 presents the 1980 population of the subregion by community.

Transportation within the Kodiak Island subregion is by air or sea. All the communities except Akhiok and Ouzinkie have landing strips; Akhiok and Ouzinkie are dependent upon sea planes or boats.

Most towns in the subregion have radio reception and rely upon radios for communication. Akhiok, Larsen Bay, and Old Harbor each have one RCA radio and a telephone. Ouzinkie has one radio-wave phone which ties into the Kodiak telephone system. Karluk has a small earth station and phone. Kodiak and Port Lions have modern telephone systems. (South Central Health Planning and Development, 1982)

Kodiak a Level III community, serves as the subregional center for transportation, communications, and human services. As such, it is the seat for the Kodiak Island Borough government, including the school system; the Kodiak Borough Health Resources Council; the Kodiak Area Native Association; and, Koniag, Inc.

Matanuska-Susitna Subregion

The Matanuska-Susitna (Mat-Su) subregion covers the same area as the Mat-Su Borough. It is bounded on the north and west by the Alaska Range, on the south by the Kenai Peninsula and Greater Anchorage Area Borough, and the Chugach mountains, and on the east by the Copper River Valley.

TABLE 9-8

POPULATION OF THE KODIAK ISLAND SUBREGION, BY COMMUNITY, WITH COMMUNITY LEVELS, 1980

Community	Level	Population
Akhiok	I	105
Karluk	I	96
Kodiak	III	4,756
Kodiak Naval Station	MR*	1,370
Larsen Bay	I	168
Old Harbor	I	340
Ouzinkie	I	173
Port Lions	I	215
Unassigned	-	2,716
SUBREGION TOTAL	-	9,939

*MR = military reservation; no community level designated.

Source: Alaska Department of Labor. Alaska Population Overview, 1981. Juneau, Alaska. 1982. Pp. 16-17.

The Mat-Su Borough is the fastest growing subregion in Alaska, having gained an average of 17.62% in population annually between 1970 and 1981. In 1981, the population stood at approximately 19,123. Only 4,786 (25.0%) of the residents lived in the incorporated communities of Houston, Palmer, and Wasilla; the remainder lived in smaller hamlets or scattered along the roads on farms or isolated residences. Over 96% of the area's population is non-Native; males make up 51.87% of the total. Forty percent are under the age of 21; 4.10% are 65 and older. (Alaska Department of Labor, 1982c)

The Mat-Su area is the primary agricultural center of the state, including dairy and truck farming. Government is the largest non-agricultural employer, accounting for 36.5% of the total work force in March, 1983. Services, particularly those associated with tourism, were second, with 33.8% of the labor force. Construction and transportation/communication/utilities were also major employers. (Alaska Department of Labor, 1983d)

Although Anchorage lies outside of the Mat-Su boundaries, it serves as the regional center for transportation, communications, and services. Within the Mat-Su subregion, most travel is by road, with rail and air being important secondary means. The Parks Highway bisects the subregion from north to south. The Glenn Highway, linking Palmer and Glennallen, runs across the southern portion of the Borough, and the Denali Highway cuts through the northeast section. Talkeetna has a small airport, while some other communities maintain airstrips. The Alaska Railroad generally parallels the Parks Highway.

The Palmer/Wasilla area is considered a hub center for purposes of planning and service development, with the two cities and their immediate vicinity jointly considered a Level III community. The other towns in the southern part of the subregion are "adjacent communities" and are linked to the Palmer/Wasilla hub for human services. Talkeetna, located on a spur road at the confluence of the Susitna and Talkeetna Rivers, is a Level I community in its own right and is not a part of the Palmer/Wasilla cluster. Table 9-9 depicts the communities of the Mat-Su subregion, with their 1980 populations. The majority of the residents live in "unassigned" areas, meaning that they are not concentrated in towns but rather are scattered in small hamlets, farms, and lodges along the highway system and in some more isolated areas.

Valdez-Cordova Subregion

The Valdez-Cordova subregion, though merged for purposes of planning and service development, actually consists of two distinct parts. The Copper River and Prince William Sound areas, though adjacent, have differing economics and traditional cultures.

Copper River Area

The communities of the Copper River area are distributed along the Copper River and the Glenn, Richardson, and Edgerton Highways. Nine rivers and numerous creeks drain this 28,887 square-mile area. The region is bounded by Canada and the Wrangell Mountains to the east, the Alaska Range to the north, the Talkeetna Mountains to the west, and the Chugiak Range to the south. (South Central Health Planning and Development, 1982)

The population of the Copper River area was 2,721 in 1981, a dramatic decrease from the high of 7,000 at the peak of the oil pipeline construction boom. Approximately 25% of the current population is Native.

Transportation in this area is primarily by road, although there are airports at Glennallen, Chitina, and McCarthy and airstrips at other locations. Most villages have radio communications, although they are unreliable in some of the more isolated places. There are few telephones.

Glennallen, a Level III community, is the subregional center for the Copper River area, serving also as the hub community for the Glennallen cluster of communities. The Copper River School District office is in Glennallen. Copper Center, an unincorporated area at the junction of the Richardson and Edgerton Highways just south of Glennallen, is the headquarters for the Copper River Native Association. (Copper River Native Association Health Department)

TABLE 9-9

POPULATION OF THE MATANUSKA-SUSITNA SUBREGION, BY COMMUNITY, WITH COMMUNITY LEVELS, 1980

Community	Level	Population
Palmer/Wasilla cluster		
Big Lake	A	410
Bodenburg Butte	A	988
Chickaloon	A	20
Houston	A	370
Kashwitna	A	200
Knik	A	10
Montana	A	40
Palmer	III*	2,141
Skwenta	A	22
Sutton	A	182
Trappers Creek	A	264
Wasilla	III*	1,559
Willow	A	139
Talkeetna	I	264
Unassigned	I	11,207
SUBREGION TOTAL	-	17,816

*III = Palmer and Wasilla considered together are a Level III community.

Source: Alaska Department of Labor. Alaska Population Overview 1981. Juneau, Alaska. 1982. Pp. 16-17.

Chitina and Mentasta Lake, though Level I communities, serve as hubs for their respective village clusters. Chistochina, also a Level I village, stands alone. Table 9-10 summarizes the communities and clusters of the Valdez-Cordova subregion, along with their 1980 populations.

Prince William Sound Area

The Prince William Sound area includes the Cordova and Prince William Sound census subareas. The area stretches from Icy Bay around the Sound to Puget Bay and is bounded by the Chugach Range and Copper River Valley to the north and the Kenai Peninsula Borough on the west. All of its communities are located on the coast.

Valdez and Cordova contained 88.1% of the area's 1980 total population of 5,627. The remainder of the people lived in Eyak, adjacent to Cordova, or in Whittier, Tatitlek, or small, isolated villages. Together, Valdez and Cordova are 82.7% non-Native. Tatitlek, on the other hand, was 77.9% Native. (Alaska Department of Labor, 1982c)

Transportation in the Prince William Sound area is by air, sea, and highway. Valdez lies at the southern terminus of the Richardson Highway. Cordova and Eyak are linked to each other by State Highway 10 and to the Richardson Highway east of Valdez by the proposed Copper River Highway. Whittier is connected to Anchorage, via Portage, by the Alaska Railroad. Valdez and Cordova have airports, and Tatitlek has sea plane access. The Alaska State Ferry System operates passenger service within Prince William Sound, with connections to Seward and Kodiak. All villages have radios; Valdez and Cordova have phones, although they are reported to be out of order about half of the time. (South Central Health Planning and Development, 1982)

There is some mining activity in the area, but most people are employed in government service, trade, and manufacturing. The Alyeska Pipeline Corporation and the Harborview Developmental Center are major employers in Valdez. In Cordova, fish processing is important. Many people throughout the area fish for commercial as well as subsistence purposes.

Valdez and Cordova are both Level III communities, with Cordova also serving as the hub for the Cordova-Eyak cluster. As first-class cities, they operate the Valdez City Schools and Cordova City Schools, respectively. The Chugiak School District is based in Whittier, a Level I community. Table 9-10 summarizes the communities and clusters of the Prince William Sound area, along with their 1980 populations.

Service Flow Patterns

Anchorage is the regional center for South Central Alaska, and virtually all communities look to Anchorage as the transportation, communications, trade, and service hub. People needing specialized health care and other services seek attention there after they have exhausted local capabilities.

Service flow patterns within the six subregions differ from place to place, often depending upon means of transportation. In the Aleutian/Pribilof subregion, the flow is usually from Level I communities directly to Anchorage; itinerant services go out from Anchorage, Unalaska, and Cold Bay to the smaller communities. For the Kodiak Island subarea, Kodiak is the base for primary inpatient services. so Kodiak is usually the first step in the flow of people seeking services beyond the capabilities of their Level I community. The Kenai Peninsula, Mat-Su, and Valdez-Cordova subregions may all be described in accordance with the cluster concept, in which people within a cluster first seek services in the cluster hub and then, if necessary, move toward the next larger community and on into Anchorage.

Available Services

Health Services

As in the central region, health services in the South Central Region are dominated by the Level IV tertiary care center. Anchorage is the major health service center for the entire state, providing virtually all diagnostic and treatment services other than open heart surgery and transplant programs. Available services vary greatly from subregion to subregion, however; subregional descriptions are provided below.

The Aleutian/Pribilof Subregion

There are six types of health care systems that deliver services within the Aleutian/Pribilof subregion:

1. The Alaska Area Native Health Service.
2. The public health nurses of the Alaska Division of Public Health.
3. The Aleutian-Pribilof Islands Association Health Department.
4. Military health care providers.
5. Community clinics.
6. Private health care providers.

Additionally, the National Health Service Corps plays a major role by providing salaries and medical backup for the physicians' assistants in Unalaska.

The Aleutian-Pribilof subregion lies entirely within the boundaries of the Anchorage Service Unit of the Indian Health Service. The Alaska Native Medical Center in Anchorage is the focus of the Service Unit. It provides ambulatory and inpatient care for Alaska Natives, providing primary care in the villages and secondary and tertiary care at the hospital itself. On St. Paul Island, the Indian Health Service operates a four-bed facility normally staffed by a physician, a nursing assistant, and several part-time employees. On St. George Island, there is a similar facility staffed by a physicians' assistant and several nursing assistants. The itinerant field health program operated by the Service Unit provides medical consultation to the community health aides. The itinerant physician sees all of the referrals from the health aides.

TABLE 9-10

POPULATION OF THE VALDEZ-CORDOVA SUBREGION, BY COMMUNITY WITH COMMUNITY LEVELS, 1980

Community	Level	Population
Copper River area		2,721
Chitina cluster		
Chitina	I	42
Lower Tonsina	A	40
McCarthy	A	16
Chistochina	I	55
Glennallen cluster		
Copper Center	A	213
Gakona	A	87
Glennallen	III	511
Gulkana	A	104
Paxson	A	30
Tazlina	A	31
Tonsina	A	135
Mentasta cluster		
Mentasta Lake	I	59
Slana	A	49
Unassigned	-	1,349
Prince William Sound area		5,627
Cordova-Eyak cluster		
Cordova	III	1,879
Eyak	A	47
Tatitlek	I	68
Valdez	III	3,079
Whittier	I	198
Unassigned	-	356
SUBREGION TOTAL	-	8,348

Source: Alaska Department of Labor. Alaska Population Overview 1981. Juneau, Alaska. 1982 p. 17.

State Public Health Nurses (PHNs) provide services to the subregion through a full-time PHN stationed in Cold Bay, as well as itinerant PHNs who make periodic visits to the Pribilofs. The PHNs promote preventive, therapeutic, and rehabilitative services to its clinics, with emphasis on communicable disease prevention, screening, and control; maternity care; family planning services; infant and child health care; turberculosis case finding and treatment supervision; school health services; developmental disabilities screening, counseling, and referral; and, mental health services.

The Adak Naval Station, located on the Andreanof Islands one thousand miles from Anchorage, has a fifteen-bed military hospital staffed by four physicians. The Adak hospital serves primarily military personnel and their dependents, although it does provide for civilians in emergencies.

The Aleutian-Pribilof Islands Association Health Department administers the following programs: 1) community health aide program; 2) emergency medical services program; 3) community health representative programs; and to 4) community health development programs.

There are three community clinics in the subregion. The Iliuliuk Family Health Service operates the only general health care facility in Unalaska. Originated by the United Methodist Church, the clinic has a nine-member community board to provide policy direction and attract funding support. The Sand Point Health Corporation governs the Sand Point clinic; its nine-member board is comprised of one city representative, one industry representative, and seven persons elected locally (six of whom must be Native). The King Cove Clinic is funded part time by the community and part time by the cannery and is staffed by a registered nurse.

The eight floating fish processors in Akutan have placed a tremendous burden on the health aide. For this reason, they fund a physicians' assistant to provide services to the processors in the area. Additionally, a private physician from Kodiak practices in Unalaska during the fishing and crabbing season.

Table 9-11 summarizes the health services available in the Aleutian/Pribilof subregion. (Aleutian-Pribilof Islands Association Health Department)

The Municipality of Anchorage

Because of its location and population base, the Municipality of Anchorage serves as a secondary and tertiary health service center for much of the state. It provides all levels of health care to the population residing in and around the Municipality.

Prevention and detection services in the Anchorage subregion include immunizations; well-adult maintenance; dental prophylaxis; family planning; tuberculosis and sexually transmitted disease screening; hypertension control; early and periodic screening, diagnosis, and treatment; vision and hearing screening; and other services. Major providers include the Alaska Native Medical Center; the Center for Disease Control; the Anchorage Neighborhood Health Center; the State Division of Public Health and Environmental Protection; the Open Door Clinic; the Anchorage School District; physicians and mid-level practitioners; voluntary health care providers; and, Providence and Humana Hospitals.

Primary medical care services include pediatrics, gynecology, prenatal care, internal medicine, and family practices. Providers include the Alaska Native Medical Center, Elmendorf Outpatient Clinic, the Anchorage Neighborhood Health Center, the Open Door Clinic, and private physicians and dentists.

Secondary and tertiary inpatient and outpatient diagnostic and treatment services are provided by the Alaska Native Medical Center, Elmendorf U.S.A.F. Hospital, Providence Hospital, and Humana Hospital. The Alaska Psychiatric Institute specializes in mental health services. Long-term inpatient services are provided by Nakoyia Health Care Center and the Pioneers' Home. The Alaska Treatment Center provides outpatient rehabilitation services. Anchorage Home Health Care offers skilled nursing care and health aide services in the home.

Table 9-11a includes a description of services available in the Anchorage area. (Municipality of Anchorage)

The Kenai Peninsula Subregion

Because the Kenai Peninsula subregion is predominantly non-Native in population, its communities are not served by the Alaska Native Health Service. The only villages with community health aides are Ninilchik and Tyonek. Some other communities receive itinerant public health nursing services under the direction of the Alaska Division of Public Health. For the most part, however, residents of the area must seek services from the private sector.

There are three hospitals on the Kenai Peninsula. Central Peninsula Hospital in Soldotna had thirty licensed beds in 1980; Seward Community Hospital also had thirty beds. South Peninsula Hospital in Homer had thirteen beds. All of these facilities provide general medical/surgical and obstetrics services. There were one physician in Anchor Point, six in Homer, one in Kenai, one in Seldovia, three in Seward, and twelve in Soldotna in 1981. Also, there were five dentists in the subregion.

In addition to acute care beds, there are 68 long-term care beds available in the Kenai Peninsula subregion. Wesleyan Nursing Home in Seward maintains 64 beds and South Peninsula Hospital in Homer has four beds. All of these beds are for intermediate care only.

The communities in the subregion which receive itinerant public health nursing services are: Anchor Point; Clam Gulch; English Bay; Hope; Nikolaevsk; Seldovia; Sterling; and, Tyonek.

Health services available in the Kenai Peninsula subregion are outlined in Table 9-11a. (South Central Health Planning and Development, 1982)

The Kodiak Island Subregion

The Kodiak Island subregion, although small in population, has a wide range of health services available through a variety of systems. The Kodiak

Island Borough operates the Kodiak Community Hospital, a 25-bed acute care facility, with a nineteen-bed intermediate long-term care unit. The Coast Guard Hospital, which serves the entire Northern Pacific Rim, has fifteen acute care beds.

A public health nurse clinic, located in Kodiak, provides itinerant services to Chiniak, Karluk, Larsen Bay, Old Harbor, Ouzinkie, and Port Lions. Port Lions also has a community clinic staffed by KANA employees and a contracted physician. Community health aides are also located in Akhiok, Karluk, Larsen Bay, Old Harbor, and Ouzinkie.

Table 9-11a summarizes health services in the Kodiak Island subregion. (Kodiak Island Native Association)

The Matanuska-Susitna Subregion

Like the Kenai Peninsula, the Matanuska-Susitna (Mat-Su) subregion is primarily non-Native. As a result, the area lacks Native health services and is entirely dependent upon State public health nurses and the private sector for health care.

Valley Hospital in Palmer, with seventeen acute care beds and six intermediate long-term care beds, is the only inpatient facility in the subregion. The Palmer Pioneers' Home provides residential services for older Alaskans. Palmer has five physicians in private practice, and Wasilla has four. There are also six dentists in the subregion.

The Alaska Division of Public Health, Section of Nursing provides itinerant services to Big Lake, Houston, Kashwitna, Knik, Montana Creek, Skwenta, Talkeetna, Trappers Creek, and Willow.

Health services available in the Mat-Su subregion are listed in Table 9-11b. (South Central Health Planning and Development, 1982)

The Valdez-Cordova Subregion

The Valdez-Cordova subregion is served by a mixture of Native, State, and private health programs. Faith Hospital, a six-bed, short-term emergency care facility in Glennallen, is owned and operated by Central Alaskan Missions. It is the only medical installation in the Copper River Basin. The medical staff is made up of a missionary doctor and nurses, a pharmacist, and a laboratory technologist. In addition to inpatient services, the hospital runs an outpatient clinic and an ambulance service.

The Alaska Area Native Health Service contracts with Faith Hospital for services to Native residents of the Copper River area. A second Native Health Service contract purchases the services of a private dentist in Glennallen during the winter. Services for Natives living within the Prince William Sound area are also provided via contracts.

In the Prince William Sound area, inpatient care is available at the fifteen-bed Valdez Community Hospital and the twelve-bed Cordova Community

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Hospital. The Cordova facility also has an eight-bed intermediate and skilled nursing care unit.

There are three physicians in private practice in Cordova, two in Glennallen, and three in Valdez.

The Harborview Developmental Center, located in Valdez, is a long-term residential care facility for the developmentally disabled. As the only center of its type in Alaska, it serves as a statewide resource.

The State Public Health Nurses provide services out of Glennallen, although not all villages are covered. Within the Copper River area, villages who have itinerant services are Chistochina, Chitina, Gulkana, Lower Tonsina, Kenny Lake, McCarthy, and Tazlina. In the Prince William Sound area, only Port Graham and Tatitlek are served.

The Copper River Native Association Health Department, operated by the Copper River Native Association, provides a variety of services to the people of its region. Categorical programs include: 1) the community health aide program, with clinics in Copper Center, Gulkana, Chistochina, Mentasta, and Cantwell; 2) alcoholism treatment; 3) homemaker services; 4) school dental services; 5) community nutrition services; and, 6) mental health services.

In the Prince William Sound area, the North Pacific Rim Health Department provides health aide and clinic services in Port Graham and Tatitlek.

Health services in the Valdez-Cordova subregion are summarized in Table 9-11b. (Copper River Native Association Health Department; North Pacific Rim Health Department)

Support Services

Support services are those services which are needed in addition to adequate medical care, educational and vocational services, and employment opportunities in order for a substantially disabled person to live independently or with his/her family. There are three major types of support services-maintenance services, developmental services, and material support services.

Table 9-11b summarizes the support services available in the South Central Region.

TABLE 9-11a

SOUTH CENTRAL REGION
HEALTH SERVICES BY COMMUNITY, 1983

Community	Level	PC	Prevention				Early Identification											
			SHE	PA	WCP	I	PNT	MDS	VHS	MTS	D&E	MS	DS	OT	PT	SSH	HHN	HHA
Aleutian/Pribilof Subregion																		
Adak Station	MR***																	
Akutan	I	L			L	L		I	I			I	I					
Atka	I	L			L	L		I	I			I	I					
Attu	I																	
Cold Bay	I	L			L	L		L	L			L	I					
False Pass	I	L			L	L		L	L			I	I					
King Cove	II	L			L	L		L	L			L	I					
Nelson Lagoon	I	L			L	L		I	I			I	I					
Nikolski	I	L			L	L		I	I			I	I					
St. George	I	L			L	L		L	L			L	I					
St. Paul	I	L			L	L		L	L			L	I					
Sand Point	II	L			L	L	L	L	L		L	L	I					
Shemya Station	MR																	
Unalaska	II	L	L		L	L	L	L	L		L	L	I					
Municipality of Anchorage	IV	L	L		L	L	L	L	L	L	L	L	L	L	L	L	L	L
Kenai Peninsula Subregion																		
Homer cluster																		
Anchor Point	A	I			I	I		I	I									
Fritz Creek	A																	
Homer	III	L			L	L	L	L	L	L	L	L	L			L		
Kachemak	A																	
Nikolaevsk	A	I			I	I		I	I									
Kenai cluster																		
Kenai	III	L			L	L	L	L	L	L	L	L	L					
Nikishka	A																	
Salamatof	A																	
Seldovia cluster																		
Halibut Cove	A																	
Seldovia	II	L			L	L	L	L	L	L	L	L	L					
Seward cluster																		
Moose Pass	A																	
Seward	III	L			L	L	L	L	L	L	L	L	L					
Soldotna cluster																		
Clam Gulch	A	I			I	I		I	I									
Cooper Landing	A																	
Kalifonsky	A																	
Kasilof	A																	
Soldotna	III	L			L	L	L	L	L	L	L	L	L					
Sterling	A	I			I	I		I	I									
Non-clustered																		
English Bay	I	L			L	L		I	I			I						
Hope	I	I			I	I		I	I									
Jakolof Bay	I																	
Ninilchik	I	L			L	L		I	I			I						
Port Graham	I	I			I	I		I	I									
Portlock	I																	
Tyonek	I	L			L	L		I	I			I	I					
Kodiak Island Subregion																		
Akhiok	I	L			L	L												
Karluk	I	L			L	L		I	I			I						
Kodiak	III	L	L		L	L	L	L	L	L	L	L	L					
Kodiak Naval Station	MR																	
Larsen Bay	I	L	L		L	L		I	I			I						
Old Harbor	I	L	L		L	L		I	I			I						
Ouzinkie	I	L	L		L	L		I	I			I						
Port Lions	I	L	L		L	L	L	L	L		L	L						

(Continue on Page 9-27)

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TABLE 9-11b
(Continue from Page 9-26)

SOUTH CENTRAL REGION
HEALTH SERVICES BY COMMUNITY, 1983

		Prevention					Early Identification											
Community	Level	PC	SHE	PA	WCP	I	PNT	MDS	VHS	MTS	D&E	MS	DS	OT	PT	SSH	HHN	HHA
Matanuska-Susitna Subregion																		
Palmer/Wasilla cluster																		
Big Lake	A	I			I	I		I	I									
Bodenburg Butte	A																	
Chickaloon	A																	
Houston	A	I			I	I		I	I									
Kashwitna	A	I			I	I		I	I									
Knik	A	I			I	I		I	I									
Montana	A	I			I	I		I	I									
Palmer	III	L	L		L	L	L	L	L	L	L	L	L					
Skwenta	A	I			I	I		I	I									
Sutton	A																	
Trappers Creek	A	I			I	I		I	I									
Wasilla	III	L	L		L	L	L	L	L	L	L	L	L					
Willow	A	I			I	I		I	I									
Talkeetna	I	I			I	I		I	I									
Valdez-Cordova Subregion																		
Copper River Area																		
Chitina cluster																		
Chitina	I	L	L		L	L		I	I									
Lower Tonsina	A	I			I	I		I	I									
McCarthy	A	I			I	I		I	I									
Chistochina	I	L	L		L	L		I	I									
Glennallen cluster																		
Copper Center	A	L			L	L												
Gakona	A	L			L	L												
Glennallen	III	L	L		L	L	L	L	L	L	L	L	L					
Gulkana	A	L	L		L	L		I	I									
Paxson	A		L															
Tazlina	A	I			I	I		I	I									
Tonsina	A																	
Mentasta cluster																		
Mentasta Lake	I	L	L		L	L												
Slana	A																	
Prince William Sound Area																		
Cordova-Eyak cluster																		
Cordova	III	L			L	L	L	L	L	L	L	L	L					
Eyak	A																	
Tatitlek	I	L			L	L	I	I										
Valdez	III	L			L	L	L	L	L	L	L	L	L					
Whittier	I																	

I = itinerant L = locally-based

PC = Prenatal care
SHE = School health education
PA = Public awareness
WCP = Well-child program
I = Immunizations
PNT = Prenatal Testing

MDS = Medical/developmental screening
VHS = Vision and hearing screening
MTS = Metabolic screening
D&E = Diagnosis and evaluation of handicapping conditions
MS = Medical services

DS = Dental services
OT = Occupational therapy
PT = Physical therapy
SSH = Speech and hearing services
HHN = Home health nursing
HHA = Home health aide services

Sources: South Central Health Planning and Development. Health Systems Plan 1982-1986. Anchorage, Alaska. 1982
Aleutian-Pribilof Islands Association Health Corporation. Tribal Specific Health Plan. Don Bantz and Associates. Anchorage, Alaska. 1979.
Copper River Native Association Health Department. Tribal Health Plan. Don Bantz and Associates. Anchorage, Alaska. 1979.
Kodiak Island Borough Health Resources Council. An Assessment of Health Care Needs, Kodiak Island Borough. Anchorage, Alaska. 1979.
Kodiak Island Native Association. Annual Report 1982. Kodiak, Alaska. 1983.
Municipality of Anchorage. Anchorage Health Systems Plan 1982-84. Anchorage, Alaska. 1982.
North Pacific Rim Health Department. Ggwangkumtenek Sungearluta. Anchorage, Alaska. 1979.

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Maintenance Services

Day care services are provided in numerous communities throughout the South Central Region through licensed centers and homes and through informal sitter arrangements. The Alaska Department of Community and Regional Affairs operates the Day Care Assistance Program to help economically stressed families to offset the high cost of child care in twelve communities. The Program supplemented child care payments for 3,889 families in these communities in FY 1983, for a total cost of $3,415,600. The average cost per child was $878. During FY 1983, eight of the children who participated in the Program were substantially handicapped. Seven of these children lived in Anchorage; one was in Kodiak. The total cost of day care assistance for the eight disabled children was $7,026.

In addition to generic day care services, an estimated 319 families in the South Central Region respite care/specialized sitter services for their substantially disabled members. There are three agencies in the region who offer respite/specialized sitter services, although their combined service capacity is only eighteen individuals at any one time. During FY 1982, these three programs served 64 families for a total of 11,095 hours. The average cost per hour of care was $23.21, although the individual program vary greatly in their costs. The total respite care budget for the region in FY 1983 was $388,964.

The Kodiak Aleutian Mental Health Center in Kodiak operates a respite care program with a capacity of three. Their estimated cost per hour is $8.47; with three families served in FY 1982 for a total of 177 hours, the budget was $1,500.

The Anchorage Respite Care Program served 36 families (41 handicapped individuals) in FY 1982. Their services are offered in a respite care center, which has a capacity of four children aged 4-12 years; in client homes, with a capacity of two; and, in the homes of service providers, also with a capacity of two. The estimated cost per hour for the three settings was $28.64 in FY 1982. The FY 1983 budget was $374,514.

The Central Peninsula Mental Health Center in Kenai administers an in-home respite care program which served 25 families in FY 1982. With a capacity of four, the program provided 2,404 hours of care at an average cost of $5.07, making a total budget of $12,200 in FY 1982. The FY 1983 budget was $12,950.

Homemaker services provide household assistance, chore service, and/or non-medical personal assistance to enable a person and his/her family to live at home. The Alaska Division of Family and Youth Services (DFYS) contracts with Alaska Management Technologies to provide homemaker services statewide. However, some communities do not yet have homemaker services available. In FY 1983, 21 towns in the South Central Region had homemaker services. The Level II communities of Sand Point, Unalaska/Dutch Harbor, Glennallen, and Valdez lacked service, as did many Level I communities. Altogether, 124 substantially handicapped individuals in the region received homemaker services in FY 1982 for an average of 107.9 hours each. The average cost per handicapped person for the year was $1,316, for a total cost of $163,184. The budget for the entire program, including clients who were not considered substantially handicapped, was $518,473.

Home health aide support is a special resource made available to individuals who need health-related personal care in order to maintain an independent, community-based living arrangement. In the South Central Region, home health aide services are provided by Home Health Care, Inc., through contract with the Alaska Division of Public Health via the Municipality of Anchorage. Services are provided only in Anchorage, Kenai, Homer, Kodiak, Palmer, and Wasilla. In FY 1983, 63 clients were served, among whom seven were substantially handicapped. The cost per client was $5,350, for a total cost for all 63 clients of $337,022. The amount directed to care of the substantially disabled was approximately $37,450.

Home Health Care, Inc., is a private, non-profit home health agency which is certified under the Medicare/Medicaid programs. The agency contracts with the Municipality of Anchorage to provide skilled nursing, related in-home services (physical, occupational, and speech therapy and medical social work), and home health aide services. Contracts with the Municipality for skilled services totalled $177,310 in FY 1983; third-party payments equalled $438,386. On the average, forty clients per month receive skilled nursing and related in-home services; the proportion of these people who are substantially disabled is unknown. The total budget for the skilled portions of Home Health Care's program in FY 1983 was $615,696.

Personal aide and attendant services provide intensive and individualized in-home personal care for persons who are substantially disabled and who, without such intensive assistance, would be unable to live in their own homes. The need for personal aides and attendant services is most urgent for mentally alert, severely physically disabled young adults who are currently residing or would otherwise be required to live in institutional settings. Approximately forty people in the South Central Region need this service. In FY 1982, for the first time in Alaska, there was a pilot program which arranged for barrier-free housing, transportation, and attendant services. The Independent Options Now program (ION), now Access Alaska, provided services to eight quadraplegic young people in Anchorage. Eight young men moved out of nursing homes ($38,000 per year each) and are now living in their own apartments. In FY 1983, the number participating rose to eleven. The average cost per client for personal aide and attendant services, transportation, and administration was $76.59 per day, or $27,956 per year, a savings of $10,044 each per year. The total budget in FY 1983 was $307,500.

In the Municipality of Anchorage, transportation services for the handicapped are provided by GSI Transportation Services, Inc., and consist of portal-to-portal and some established route services, using vehicles with wheelchair lifts. Other transportation services in Anchorage and elsewhere in the region are provided in conjunction with residential, recreation, school, senior center, and other programs.

Recreational services for the disabled are generally provided in conjunction with other programs, residential centers, and schools. There are a few programs specifically for the handicapped in the South Central Region, however. The Kodiak Aleutian Mental Health Center has a leisure time training component built into its residential training component. This program also involves disabled young adults from the community who are not facility residents. The program promotes use of community facilities such as swimming pools, parks, concerts, and sports events, as well as parties, games, dinners, and other activities internal to the center.

The Anchorage Municipal Recreation Program offers extensive programming for the handicapped, including sports, physical fitness, arts and crafts, and the Special Olympics program. The Handicapped Sports and Recreation Association, also based in Anchorage, organizes ski trips, camping, hiking, and other outings.

The Association for Retarded Citizens of Kodiak holds the Special Olympics in its area. Other communities, such as Kenai, also participate regularly in Special Olympics training and activities. In rural parts of the region, there are few recreation programs especially designed for disabled people outside of the schools.

Developmental Services

Developmental services are provided by the school district and by the various agencies as adjuncts to their generic services for the handicapped. Also, the Kodiak Aleutian Mental Health Center offers special living skills training for an average of 12.5 clients monthly. The Kodiak program includes a leisure time training component.

Material Support Services

Cash assistance is available to eligible individuals and families in the South Central Region on the same basis as elsewhere in the state. The major categories of special assistance to the handicapped are Aid to the Disabled and Aid to the Blind, through the Alaska Division of Public Assistance, and Supplemental Security Income (SSI) payments, in accordance with the federal Social Security Act.

Personal adaptive equipment is provided to disabled children through Alaska's Handicapped Children's Program. The State Division of Vocational Rehabilitation supplies personal and environmental equipment and home retro-fits for disabled adults who have vocational rehabilitation potential. Voluntary health agencies such as the Multiple Sclerosis Society have "loaner" equipment or, in some cases, will purchase and install environmental adaptive equipment for individuals who meet their eligibility criteria. For other people, particularly adults with little vocational potential, adaptive equipment is generally unavailable except through private or third-party payment or on an informal basis. Other than the Handicapped Children's Program, all adaptive equipment services are virtually unavailable outside of the Anchorage area.

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TABLE 9-12

SUPPORT SERVICES AVAILABLE IN THE SOUTH CENTRAL REGION, FY 1983

Type of Service	Availability*	Substantially Handicapped Clients Served	Average Cost Per Client	Total Costs for Handicapped Clients
MAINTENANCE SERVICES				
Day Care/sitter	A	NR	NR	NR
Day Care Assistance Program	P	8	$878	$7,026
Respite/specialized sitter	P	64	$23.21/hour	$388,964
Homemaker	P	124	$1,316	$163,184
Home health aide	P	7	$5,350	$37,450
Home health nursing	P	NR	NR	NR
Personal aides and attendants	P	11	$27,956	$307,500
Transportation	P	NR	NR	NR
Recreation	P	NR	NR	NR
LIVING SKILLS TRAINING SERVICES	P	NR	NR	NR
MATERIAL SUPPORT				
Financial Assistance	A	NR	NR	NR
Environmental adaptive equipment	P	NR	NR	NR
Personal adaptive equipment	P	NR	NR	NR

* A = available; P = available in only some parts of the region; U = unavailable.

Residential Services

Services Available in the South Central Region

As in other regions, 95% of the disabled people in the South Central Region live at home in natural environments. The other five percent seek care in a variety of settings, ranging from augmented to protective environments.

The South Central Region has more services of every type available than any other part of the state. Because of the presence of Anchorage, with almost half of the state's population, and Valdez, which has Harborview Developmental Center, the South Central Region contains many disabled people whose home communities lie far away from where they are currently living. Altogether, there are eighteen augmented, devised, and protective environments in the South Central Region housing almost 300 persons with substantial handicaps.

There are seven types of augmented residential environments available within the South Central Region. Each of these options is described briefly below and in Table 9-13.

The Alaska Division of Family and Youth Services (DFYS) offers subsidized adoptions to enable adoptive placement of children who require medical services beyond the financial abilities of their adoptive families. During FY 1983, there was one child in an subsidized adoptive placement in the South Central Region. The average cost per client day in subsidized adoptions was $9.86.

The DFYS also provides foster care for substantially disabled children and youth. Although children in these placements are not so impaired that they require specialized foster care, they do need placement outside of their natural families. During FY 1983, there were ten substantially disabled children in foster care in the South Central Region. The average cost per client day in foster care was $14.28.

Access Alaska operates an Apartment Program in Anchorage. During FY 1983, three adults participated in this program. Two of them were residents of the South Central Region prior to entering the apartment program; the other person was from the southeast region. Average daily costs per resident were $124.01.

Access Alaska also has an Independent Living Program in Anchorage. This program assists disabled adults to achieve necessary skills and then to live on their own in the community. Eight people took part in this program in FY 1983. Five of them were residents of the South Central Region; one was from the northern region; and, two were from out of state.

The Hope Cottages Independent Living Program enables severely handicapped adults to live in their own residences. Although these individuals may live with other people, the situation is characterized by the fact that the handicapped person needs very little assistance from others to manage his or her own life. In FY 1983, 31 people participated in this program. Twenty of them were South Central Region residents. Four were from the southeast region, two from the central region, and four from the western region. The home community of one client was unknown. The average cost per client day was $24.10.

The Hope Cottages Foster Care Program provides specialized foster care services to twelve severely disabled young people. Through the program, the handicapped individuals are placed in homes with foster parents who have received extensive training in the needs of their particular charges. Of the twelve clients in the Anchorage program in FY 1983, six were residents of the South Central Region, two were from the southeast region, and four were from the central region. Average daily costs per client were $72.30.

The ARMSI-Satellite Home Program also offers specialized foster care services in the Anchorage area. In FY 1983, this program served six individuals. This is the only program located in the South Central Region which had no clients who considered the region as their home community. Of the six participants, one was from the central region, three from the western region, and two from the northwest region. The average daily costs per client were $83.14.

There were eight programs offering residential services in devised environments in the South Central Region in FY 1983. Each of these options is briefly outlined below and in Table 9-13.

Hope Cottages Adult Group Homes in Anchorage administers several separate homes, each with four beds. These facilities provide group living situations which promote independent functioning of each resident to the extent possible for that person while still giving support and structure to activities of daily life. During FY 1983, 36 adults resided in the various homes. Nineteen of these individuals were South Central Region residents. The others included two from the southeast region; one each from the central, southwest, northwest, and northern Regions; four from the western region; and, seven whose home communities were not identified. The average cost per day for each client was $75.57.

The Hope Cottages Children's Group Homes, also in Anchorage, are very similar to the adult group homes, but they are designed for children and youth aged 6-20. There were sixteen young people enrolled in this program in FY 1983. Seven of them were South Central Region residents. Of the remaining nine, two each were from the southeast, central, and western Regions; and, one each were from the northwest and northern regions and out of state. The average cost per client per day for these children was $90.91.

The Kodiak Baptist Mission, which is generally not designed for substantially disabled people, served one severely handicapped individual in FY 1983. This person was from the northwest region. The average cost per day for his care was $61.61.

TABLE 9-13

UTILIZATION OF SOUTH CENTRAL REGION RESIDENTIAL FACILITIES, BY HOME REGION OF CLIENTS WITH SUBSTANTIAL HANDICAPS, FY 1983

		Number of Clients by Home Region									
Program by Type of Environment	Location	SE	SC	C	SW	W	NW	N	Out of State	Unknown	Total
AUGMENTED											
Access Alaska Apartment Program	Anchorage	1	2	0	0	0	0	0	0	0	3
Access Alaska Independent Living Program	Anchorage	0	5	0	0	0	0	1	2	0	8
Hope Cottages Independent Living Program	Anchorage	4	20	2	0	4	0	0	0	1	31
Hope Cottages Foster Care Program	Anchorage	2	6	4	0	0	0	0	0	0	12
ARMSI Satellite Home Program	Anchorage	0	0	1	0	3	2	0	0	0	6
DFYS Subsidized Adoptions	SC Region	0	1	0	0	0	0	0	0	0	1
DFYS Foster Care	SC Region	0	10	0	0	0	0	0	0	0	10
DEVISED											
Hope Cottages Adult Group Homes	Anchorage	2	19	1	1	4	1	1	0	7	36
Hope Cottages Children's Group Homes	Anchorage	2	7	2	0	2	1	1	1	0	16
Kodiak Baptist Mission	Kodiak	0	0	0	0	0	1	0	0	0	1
Heritage House Boarding Home	Anchorage	0	2	0	0	0	0	0	0	0	2
Anchorage Boarding Home	Anchorage	0	2	0	0	0	0	0	0	0	2
Charles Boarding Home	Palmer	0	19	0	0	0	0	0	0	0	19
The Lodge Boarding Home	Anchorage	0	8	0	0	0	0	0	0	0	8
Parridor Boarding Home	Anchorage	0	3	0	0	0	0	0	0	0	3
PROTECTIVE											
Harborview Developmental Center	Valdez	9	40	10	1	7	7	2	5	5	86
Hope Cottages ICFs-MR (3 ten beds)	Anchorage	2	16	4	1	6	1	0	0	0	30
Nakoyia Health Care Center	Anchorage	2	8	5	1	1	0	0	4	4	25
Wesleyan Nursing Home	Seward	1	3	2	0	0	2	1	0	0	9
TOTAL		25	171	31	4	27	15	6	12	17	308

Sources: Governor's Council for the Handicapped and Gifted. Surveys of Provider Agencies, January - June, 1983. Fairbanks, Alaska. July, 1983.
Alaska Department of Health and Social Services, Division of Management and Budget. A Study of Alaska's Adult Residential Care Facilities. Juneau, Alaska. August, 1982.

The Heritage House Boarding Home is a residential facility in Anchorage for people over the age of eighteen. It provides three meals per day; housekeeping and laundry services; transportation and shopping services; recreational and meeting space; referrals to physicians, medical facilities, and social service and employment agencies; and, aid in developing life skills for independent living. The building is a six-plex apartment house, including ten double bedrooms and five single bedrooms. In FY 1983, Heritage House served two people who were considered substantially handicapped. Both of these individuals were South Central Region residents prior to entering the boarding home. The average cost per day for each of these clients was $29.00.

The Anchorage Board Home is similar in services and facilities to the Heritage House program. It also served two substantially disabled people in FY 1983, at an average cost per client day of $29.00.

The Charles Boarding Home in Palmer provided residential and boarding care to nineteen substantially handicapped individuals during FY 1983. Their average daily rate was also $29.00.

The Lodge, located in Anchorage, serves fairly low-functioning but independent clients. The Lodge has a maximum capacity of 27, and it served 32 different individuals in FY 1982. Six of these people were developmentally disabled; two were physically disabled; and, the remainder had psychiatric and other problems. The facility consists of one large and two small buildings. Residents frequently have duties in the building, such as cooking or maintenance. The average cost per client day was $29.00

Parridor Boarding Home, also in Anchorage, cares mostly for mentally ill persons who are too disruptive for other facilities. The maximum occupancy is thirty people. During FY 1982, Parridor served 23 individuals, two of whom were developmentally disabled and one of whom was physically disabled. The average cost per client day was $29.00.

Finally, there were four facilities in the South Central Region which provided protective residential services. Each of these facilities is sketched below and in Table 9-13.

The Harborview Developmental Center is the State-operated institution for the developmentally disabled. It has a capacity of 96 and is licensed as an Intermediate Care Facility-Mentally Retarded (ICF-MR). This facility serves the entire state and accepts people of all ages. During FY 1983, Harborview cared for 86 individuals. Forty of these people considered the South Central Region to be their home. The others reported home communities as follows: nine from the southeast region; ten from the central region; one from the southwest region; seven each from the western and northwest regions; two from the northern region; five from out of state; and, five whose home communities were unknown. The average cost per client day at Harborview was $237.05.

Hope Cottages ICF-MR consists of Hope Park, Forest Park and Ocean Park, three facilities located in Anchorage. Together the facilities have a capacity of thirty and serve severely handicapped children from birth to age eighteen. In FY 1983, thirty children were served, of whom sixteen were from the South Central Region. The remaining fourteen were from the southeast region (2), the central region (4), the southwest region (1), the western region (6), and the northwest region (1). The average cost per client per day was $188.53.

Nakoyia Health Care Center, recently purchased by the Sisters of Providence (Providence Hospital), is a 216-bed skilled and intermediate care facility in Anchorage. In FY 1983, 25 of its residents were considered to be substantially disabled according to the definitions used in this plan. These people came from all over Alaska and from out of state. The average daily cost per intermediate care resident was $119.00.

Wesleyan Nursing Home in Seward has a licensed capacity of 64 beds, all of which are designated for intermediate care. During FY 1983, this facility cared for nine individuals who were substantially disabled according to the definitions used in this plan. The residents included three from the South Central Region; one each from the southeast and northern regions; and, two each from the central and northwest regions. The average daily cost per resident was $68.82.

Table 9-13 shows utilization experience of residential facilities/programs in the South Central Region, by home region of the clients.

Facilities Utilized by Residents of the South Central Region

Despite the presence of a wide range of residential options in the South Central Region, some local residents choose to participate in programs outside of their home communities. Although the majority of substantially handicapped people in the South Central Region who need residential placements stay in Anchorage, Seward, or Valdez, some travel as far as Ketchikan, Juneau, and Fairbanks. Altogether, 182 South Central Region residents lived in augmented, devised, or protective environments during FY 1983. Almost 94% of these people were placed within their home region. The other six percent were in Fairbanks, Ketchikan, Wrangell, and Juneau.

Table 9-14 outlines all the residential placements of residents of the South Central Region during FY 1983.

Residential Service Needs of South Central Region Residents

In the South Central Region, as Table 9-15 shows, approximately 235 individuals needed some form of residential assistance in 1983. One hundred five people received this care in their home region; 117 remained without service. The gap between services needed and received is greatest in the "augmented" category, where 96 people needed service but only twenty received any. The problem is almost reversed in the "protective" category, where 62 people needed such care but 54 received it. However, despite the fact that some people apparently received a level of care which exceeded their needs, there were others who were estimated to need protective environments but who were not served.

It should be noted, however, that forty percent or 34 Harborview residents are considered "over-placed" by the Division of Mental Health and Developmental Disabilities.

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TABLE 9-14

RESIDENTIAL PLACEMENTS OF SOUTH CENTRAL REGION RESIDENTS WITH SUBSTANTIAL HANDICAPS, FY 1983

Program by Type of Environment	Location	Number of Residents by Age Group 0-5	6-20	21-64	65+	Total
AUGMENTED						
FRA Specialized Foster Care Program	Fairbanks	0	0	1	0	1
Hope Cottages Foster Care Program	Anchorage	0	6	0	0	6
Hope Cottages Independent Living Program	Anchorage	0	0	20	0	20
DFYS Subsidized Adoption Program	SC Region	0	1	0	0	1
DFYS Foster Care	SC Region	0	10	0	0	10
Access Alaska Apartment Program	Anchorage	0	0	2	0	2
Access Alaska Independent Living Program	Anchorage	0	0	5	0	5
DEVISED						
Anchorage Boarding Home	Anchorage	0	0	2	0	2
Charles Boarding Home	Palmer	0	0	19	0	19
Heritage House Boarding Home	Anchorage	0	0	2	0	2
The Lodge Boarding Home	Anchorage	0	0	8*	0	8*
Parridor Boarding Home	Anchorage	0	0	3*	0	3*
Hope Cottages Children's Group Home	Anchorage	0	7	0	0	7
Hope Cottages Adult Group Homes	Anchorage	0	0	18	0	18
FRA Group Homes	Fairbanks	0	0	7	0	7
Gateway Opportunity Center Group Home	Ketchikan	0	0	1	0	1
PROTECTIVE						
Wrangell Long Term Care Facility	Wrangell	0	0	2	0	2
St. Ann's Nursing Home	Juneau	0	0	1	0	1
Nakoyia Health Care Center	Anchorage	1	0	6	0	7
Wesleyan Nursing Home	Seward	0	0	3	0	3
Careage North Health Care Center	Fairbanks	0	0	1	0	1
Harborview Developmental Center	Valdez	0	6	34	0	40
Hope Cottages ICF-MR	Anchorage	1	15	0	0	16
TOTAL		2	45	135	0	182

* = Does not count mentally ill residents.

Sources: Governor's Council for the Handicapped and Gifted. Survey of Provider Agencies, January - June, 1983. Fairbanks, Alaska. July, 1983.
Alaska Department of Health and Social Services, Division of Management and Budget. A Study of Alaska's Adult Residential Care Facilities. Juneau, Alaska. August, 1982.

TABLE 9-15

NUMBERS OF SUBSTANTIALLY HANDICAPPED PERSONS NEEDING AND RECEIVING RESIDENTIAL PLACEMENTS, SOUTH CENTRAL REGION, 1983

	Number of People				
Placement by Age Group	Needing Service	Receiving Service in Home Region	Receiving Service Outside Home Region	Unserved	Unserved in Home Region
AUGMENTED ENVIRONMENT					
0-5	16	0	0	16	16
6-20	24	7	0	17	17
21+	56	12	1	43	44
All ages	96	19	1	76	77
DEVISED ENVIRONMENT					
0-5	13	0	0	13	13
6-20	19	7	0	12	12
21+	45	29	8	8	16
All ages	77	36	8	33	41
PROTECTIVE ENVIRONMENT					
0-5	10	1	0	9	9
6-20	16	6	0	10	10
21+	36	43	4	[11]	[7]
All ages	62	50	4	8	12
TOTAL	235	105	13	117	130

[ ] = number of people in protective environments who are estimated to need a less restrictive setting.

Source: Governor's Council for the Handicapped and Gifted, FY 81-82 DD State Plan. Fairbanks, Alaska. Chapter 6.
Surveys of provider agencies. January, 1983.
Analysis of special education and residential placement data. June, 1983.

Costs of Residential Services Provided in the South Central Region

In most instances, services provided in augmented environments are less expensive than those in devised or protective environments. However, except in the case of Hope Cottages Independent Living Program, this is not true in the South Central Region. Generally speaking, devised residential services in this region are the least expensive, followed by augmented programs and protective programs.

In FY 1983, the State budgeted $1,269,373 for the care of substantially handicapped persons in augmented environments in the South Central Region. Average daily costs per resident varied widely from program to program, ranging from $24.10 in the Hope Cottages Independent Living Program to $124.01 at Access Alaska's Apartment Program and Independent Living Program, which are designed for severely disabled people who require attendant services and a range of other kinds of assistance.

Devised environment programs in the South Central Region ranged in average cost per client day from $29.00 at the five boarding homes to $90.91 at the Hope Cottages Children's Group Homes. During FY 1983, the State budgeted $1,762,549 to provide devised residential services in the South Central Region.

In FY 1983, the four protective residential programs in the South Central Region received a total of $10,817,152 to cover the costs of care for substantially disabled individuals. The Harborview Developmental Center in Valdez was the major supplier of services and accounted for $7,440,800 in expenditures, or almost 69% of the total.

Table 9-16 depicts all costs and funding sources for residential services provided in the South Central Region in FY 1983.

TABLE 9-16

COSTS AND FUNDING SOURCES FOR RESIDENTIAL SERVICES PROVIDED IN THE SOUTH CENTRAL REGION, FY 1983

Facility/Program	Funding Source	FY 1983 Budget		Average Daily Cost
AUGMENTED				
Access Alaska Apartment Program	State DOE/DVR General Fund	$200,000	$497,900	$124.01
	State DHSS/GR Med. General Fund	87,500		
	Federal Independent Living Fund	95,000		
Access Alaska Independent Living Program	Federal/State AD/SSI	66,000		
	Federal ASHA Subsidy	29,400		
	Municipality of Anchorage	20,000		
Hope Cottages Independent Living	State General Fund	272,711		24.10
Hope Cottages Foster Care Program	State General Fund	316,680		72.30
ARMSI-Satellite Home Program	State General Fund	182,082		83.14
DEVISED				
Hope Cottages Adult Groups	State General Fund	886,103	$1,103,303	75.57
	Federal SSI	201,600		
	Private	15,600		
Hope Cottages Children's Group Homes	State General Fund	477,029	530,908	90.91
	School District	41,075		
	Private	12,804		
Kodiak Baptist Mission	State General Fund	22,488		61.61
Heritage House Boarding Home	State General Fund	21,170		29.00
Anchorage Boarding Home	State General Fund	21,170		29.00
Charles Boarding Home	State General Fund	21,170		29.00
The Lodge Boarding Home	State General Fund	21,170		29.00
Parridor Boarding Home	State General Fund	21,170		29.00
PROTECTIVE				
Harborview Developmental Center	Federal Title XIX	1,896,600	7,440,800	237.05
	State General Fund	5,440,200		
	Other	104,000		
Hope Cottages ICF-MR	Federal Title XIX	1,032,201	2,064,403	188.53
	State General Fund	1,032,201		
Nakoyia Health Care Center	Federal Title XIX	542,937	1,085,875	119.00
	State General Fund	542,938		
Wesleyan Nursing Home	Federal Title XIX	113,037	226,074	68.82
	State General Fund	113,037		
GRAND TOTAL, ALL SETTINGS		$13,849,074		--

Sources: Governor's Council for the Handicapped and Gifted. Survey of Provider Agencies, January - June, 1983. Fairbanks, Alaska. July, 1983.
Alaska Department of Health and Social Services, Division of Public Assistance. Monthly Nursing Home Census and Per Diem Rates. Juneau, Alaska. 1983.
Alaska Department of Health and Social Services, Division of Management and Budget. A Study of Alaska's Adult Residential Care Facilities. Juneau, Alaska. August, 1982.

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Educational Services

Infant Learning Program

Six infant learning programs served 251 infants and young children under age three in the South Central Region in 1982. Over 365 children were screened for developmental delays or disabilities, approximately one-half of the total number of children estimated to be in the "at-risk-of-delay" target population. Three within the South Central Region areas do not have infant learning programs: Valdez-Cordova; Aleutian-Pribilof Islands; and the villages on Kodiak Island. Programs active in FY 1982 are summarized in Table 9-17.

In Anchorage, the Alaska Treatment Center (ATC) is the grantee of the Division of Public Health for Infant Learning Program.

The ATC Infant Learning Program serves the Anchorage bowl area and, if caseload permits, will serve infants and children who live outside of any Infant Learning Program designated geographic area and who come to Anchorage on a regular basis for medical or therapy reasons. An average of thirteen referrals per month were received in FY83. In FY82, 133 children were served.

The program had three parent groups, each six weeks long, which ran concurrently at ATC one night a week in March and April 1983. They were a Parent Information Series on Motor Delays, a Speech/Language Parent Group, and a Parent Information Series on Down's Syndrome. These programs offered opportunities for learning and mutual support in addition to those provided by the teachers during the regular home visits. Emotional support is often an extremely important component, as one mother noted:

> "As a mother of a multi-handicapped child, I would like to give an additional thanks to my son's teacher for the emotional support she has given me during the rough periods. Just having someone to talk to who understands my son and his problems is a great emotional release."

Despite the larger numbers of handicapped children in an urban area, each parent can feel isolated and alone without people such as the infant learning teacher to offer guidance and be a sounding board.

The ATC Infant Learning Program employs a teacher/supervisor, five full-time and one half-time teachers, and a secretary. The program services were started in 1975 and were provided by the Alaska Resources (ARMSI) and the Alaska Developmental Center until ATC received the grant in 1981.

ATC is the state's oldest private, non-profit out-patient rehabilitation center (started in 1946). A total of 65 professional and support staff offer evaluation and therapy in physical and occupational therapy, speech/language pathology, audiology, psychology, and education services. The ATC facility in Anchorage is barrier-free and contains classrooms, treatment rooms, kitchens, a gym, therapeutic pool, playground, offices, and specialized equipment. In January 1983, ATC was certified as a Medicare Comprehensive Out-Patient Rehabilitation facility, the first facility in the nation to receive such certification means Medicare-eligible individuals may obtain any of the services at ATC and have those services reimbursed by Medicare.

Chugiak Children's Services, a non-profit corporation organized in 1971, provides services to and for young children and their families residing between Eagle River and Eklutna. The range of services include Head Start (34), Pre-School Enrichment (90), and a pre-school for local handicapped children (8).

Infant Learning enrollments have tripled since 1980:

Year	Enrollment	
FY 1980	10	
FY 1981	17	
FY 1982	20	
FY 1983	27	(as of March 31, 1983)

The program is home-based, with home visitors going to each child's home on a weekly basis or as determined by a multidisciplinary evaluation of the child's needs. Each family signs a request for services, participates in developing an individual program, and is the center of focus as the child's teacher. These characteristics are common to the other infant learning programs and required or encouraged by State program regulations and guidelines.

For FY 1984, a third teacher will be added to keep pace with the increased referrals and enrollment.

In Homer and the surrounding area, the South Peninsula Mental Health Association provides infant learning services. The diverse communities of English Bay, Port Graham, Seldovia, Anchor Point, Nikolaevsk, and Ninilchik each have identified infants who are delayed or disabled and need infant stimulation services. One full-time teacher served eight children during the first nine months of FY 1983. The rapid rate of local population increase-30% over the last two years-means community services will need to be expanded to meet needs. The Infant Learning Program and the Mental Health Center's Parent-Child Education and Training Classes are well-received in the villages and in Homer.

The Central Peninsula Mental Health Center is the multi-service agency which sponsors the Infant Learning Program in Kenai, Soldotna, Sterling, Kasilof, Moose Pass, Cooper Landing, and Seward. Each Infant Learning Program must have child-find outreach activities to make the community aware of services, to identify children who might need services, and to screen and assess those children prior to enrollment in the program. The Central Peninsula infant learning teacher works with the local Association for the Handicapped and coordinates the Developmental Disabilities Advisory Group, which advises the Mental Health Center on its community service components, including the Infant Learning and respite care services. Parents and professionals work together to review program goals and needs and to develop and support these programs.

TABLE 9-17

SOUTH CENTRAL REGION
INFANT LEARNING PROGRAM ENROLLMENT STATISTICS, FY 1982

		Total Pop. 0-2	Disabled Children						ILP Utilization		Funding (in thousands)		
Community	Agency	FY80	At Risk	DD	Screened Svd	Enrolled	T	MDE	Contact Hours	Number Home Visits	FY82	FY83	FY84
Anchorage	Alaska Treatment Center	10,356	515	309	186	133	57	57	2,590	1,420	166.6	201.0	271.8
Chugiak	Chugiak Childrens Svcs.				25	20	7	3	609	311	41.0	32.8	91.1
Homer	South Peninsula Mental Health Center	1,514	75	45	4	2	0	0	245	4	18.8	49.0	54.6
Kenai	Central Peninsula Mental Health Center				39	18	5	4	542	204	20.0	24.5	70.3
Kodiak	Association for Retarded Citizens	635	32	19	83	55	20	38	562	216	20.0	23.1	31.0
Mat-Su Valley	Association for Retarded Citizens	1,146	57	34	42	35	9	6	547	362	43.0	44.7	47.5
Valdez-Cordova		473	24	14	0	0	0	0	0	0	0	0	0
Aleutian-Pribilof		401	20	12	0	0	0	0	0	0	0	0	0
TOTAL		14,525	723	433	379	263	98	108	5,095	2,517	309.4	375.1	566.3

DD = developmentally delayed; T = terminated; MDE = received multi-disciplinary evaluations.

Sources: Division of Public Health, Infant Learning Program Year-End Report, FY82. Anchorage, Alaska. September, 1982.
Division of Public Health, FY84 budget allocations, Infant Learning Program Coordinator. Anchorage, Alaska. August, 1983.

The Kodiak Infant Learning Program is operated by the Association for Retarded Citizens. A half-time teacher serves an average of ten children. The target areas for services are the community of Kodiak and the Coast Guard base located on Kodiak Island. The major identified needs of the children are language development, motor stimulation, physical therapy, cognitive stimulation, self-care skills, and behavior training. Weekly home visits involve the parent as the primary teacher and provide the parent with materials, instruction, and an opportunity to evaluate progress.

The Kodiak ILP teacher has met with representatives in the villages on Kodiak Island and determined there is a need for ILP services in the villages. It is expected that the Kodiak Area Native Association, which provides preschools in the villages, will apply for an ILP grant for FY 1985.

Valley Association for the Retarded (ARC) is a non-profit, consumer-oriented organization which provides families of developmentally disabled individuals with direct access to a support group and to information regarding services and programs available locally. Valley ARC has sponsored the Mat-Su Infant Learning Program since it originated in March, 1979. Target groups are defined in the grant proposal as:

1. Established risk - infant has an early-appearing aberrant condition that is directly related to a diagnosed medical condition, e.g. Down's Syndrome.

2. Biological risk - infant or child presents a history of prenatal, neonatal, and/or early development events suggestive of an increased probability of central nervous system insult or developmental delay due to adverse perinatal life, e.g., prematurity.

3. Environmental risk - biologically sound infants or children whose early experience, e.g., maternal bonding and stimulation, yield a high probability for developmental delay. Enrollment figures were:

Year	Enrollment	
1979	8	
1980	15	
1981	16	
1982	35	
1983	28	(end of eight months)

As part of its community awareness and outreach efforts, the Mat-Su program compiled and edited a slide presentation which was shown to the local high school home economics classes and to community groups.

Through flexible scheduling, staff provide for interaction with family members not available for regular daytime visits.

A total of 379 South Central Region infants and children were screened in FY 1982. 263 were enrolled in Infant Learning Programs which the Alaska Division of Public Health funded at $309,000 through grants to local organizations. In FY 1984 $566,000 is allocated for South Central Region. This substantial increase corresponds to the increased population of the region and the increased rate of referrals and demands for services. Program costs are expected to increase from $1400 per child per year to about $2,500 per year as program funding will allow hiring of additional teachers and support staff to try to meet the recommended child:teacher ratio of 15:1.

Pre-School

The South Central Region has six Head Start programs. The Anchorage Head Start serves 31 handicapped children, with two of these classified as emotionally disturbed and one as hard of hearing. The rest have speech and language impairments. Cook Inlet Native Association operates Head Starts at two locations in Anchorage, with six speech/language impaired children enrolled. The Chugiak Head Start has twelve handicapped students, including one visually impaired child. Alakanuk has none of its 22 children identified as handicapped. Kodiak has three, and Seward, two, all speech/language impaired. Cost per child of Head Start programs in the South Central Region in FY 1983 was $2,955. Enrollments in these programs are summarized in Table 9-18.

Anchorage School District reported 222 pre-school handicapped children ages three through five.

TABLE 9-18

PRE-SCHOOL HANDICAPPED CHILDREN, AGES 3-5
SOUTH CENTRAL ALASKA SCHOOL DISTRICTS, 1982-83 SCHOOL YEAR

Disability	Anchorage	Kenai	Kodiak	Mat Su	Total
MR	20	5		3	28
HH	4				4
D	7		1		8
SI	133	62	8	20	123
VH	3				3
SED	2(?)				2(?)
OH	17	1		6	24
OHI	4	1			5
SLD	28		1		29
DB					0
MH	6		2		8
TOTAL	222	69	12	29	332

MR = Mentally Retarded
D = Deaf
VH = Visually Handicapped
OH = Orthopedically Impaired
DB = Deaf/Blind
MH = Multiply Handicapped

HH = Hard of Hearing
SI = Speech Impaired
SED = Seriously Emotionally Disturbed
OHI = Other Health Impaired
SLD = Specific Learning Disability

Source: Alaska Department of Education; school district reports, 1983.

A total of 332 handicapped pre-schoolers were identified and served by these four districts. The remaining South Central school systems served a combined total of twenty handicapped pre-schoolers in the 1982-83 school year.

Chugiak Children's Services added a pre-school in 1981 and is under contract to the Anchorage School District. It eliminated the need for these very young children to be transported to Anchorage to attend classes, a ride which for some amounted to two-to-three hours per day.

Special Education

Legal school age for children with handicaps in Alaska begins at age 3 and continues through age 19. Local school boards have the discretionary power to admit children under or over this statutory school age. Public Law 94-142, the Education for All Handicapped Children Act, requires provision of education and related services appropriate to individual needs and at public expense.

In South Central Alaska in the 1982-83 school year, 11% of the total students enrolled in school, or 6,343 students, received special education services. Students totaled 4,023 in Anchorage, 862 in Kenai, 368 in Kodiak, and 588 in Mat-Su. These enrollments are shown in Table 9-19.

Other than speech-impaired students (1,663) or learning disabled students (3,866), the largest number of students in any exceptionality category were those with mental retardation (236). For districts other than Anchorage, the number of children with any one particular disability ranged from a low of one to four students, to a high range of 18 to 29. Both large and small districts in Alaska must develop specialized resources for few students in order to provide the required special education services locally.

Only five per thousand special education students, including the Anchorage students who are served at the specialized programs and facilities in the Anchorage area, are served outside of their home district. Therefore local service is the rule, not the exception, even for severely handicapped students. Fourteen of the thirty students placed out of district are out-of-state at different specialized residential schools. When high costs of local special education are cited, it is important to note that out of state placements cost the Department of Education an average of over $16,000 per student. When residential costs are added, total costs may approach $70,000 or $80,000 annually. This cost is similar to in-state out of district placements. Exact figures are hard to develop because student population in state contract programs fluctuates; some students are in programs year-found while others arrive after school starts and leave during the year. Students from Anchorage are counted with students from other districts. Residential travel and medical costs may be borne by several different agencies.

TABLE 9-19

1982-83 SPECIAL EDUCATION ENROLLMENT INFORMATION
SOUTH CENTRAL REGION

School District	Number of Schools	Total Enroll-ment	Number of Sp Ed Students	% of Total Enroll-ment	Exceptionality											
					MR	HH	D	SI	VH	SED	OI	OHI	SLD	DB	MH	Out of District
LEAs																
Anchorage	69	37,360(1)	4,023	11	156	54	45	1,035	12	117	73	16	2,445	12	58	85#
Cordova	2	440	61	14	2			10		5	1	1	42			
Kenai	26	7,026	862	12	18	3	4	270	4	48	29	6	480			9
King Cove	2	135	27	20	1	2		7					17			
Kodiak	12	2,215	368	17	12		2	110	2	26	2	1	210		3	3
Mat-Su	19	5,830	588	10	24			119	5	8	20		412			7
Sand Point	2	118(2)	5	4									5			
Unalaska	2	179	34	19	1			16					17			1
Valdez	5	880	86	10	8	1		29					48			
REAAs																
Adak	3	591	81	14	1			41	1		1		37			
Aleutian Chain	6	138	18	13	3	1		2					12			
Chugiak	2	66	10	15				2					8			
Copper River	8	564	137	24	6			15	1	3	1	1	107		3	
Pribilof	2	176	43	24	4			7		3			26		3	1
TOTALS		55,718	6,343*	11	236	61	51	1,663	25	210	127	25	3,866	12	67	106

** Does not include out-of-district placements.

Most Anchorage "out-of-district" placements are still residing in Anchorage. This category includes children placed at the following Anchorage-area contract facilities: API, School for the Deaf, McLaughlin Youth Center, Jesse Lee Home.

(1) Includes 309 children attending school on military bases within the Anchorage corporate limits.

(2) Includes 5 children who originally attended Aleutian Chain REAA and are still counted for purposes of receiving 89-313 funding.

MR = Mentally Retarded
HH = Hard of Hearing
D = Deaf
SI = Speech Impaired
VH = Visually Handicapped
SED = Seriously Emotionally Disturbed
OI = Orthopedically Impaired
OHI = Other Health Impaired
SLD = Specific Learning Disability
DB = Deaf/Blind
MH = Multiply Handicapped

Sources: Alaska Department of Education. 1982-83 School Year, P.L. 94-142 Count. Juneau, Alaska. December, 1982.
Alaska Department of Education. 1982-83 School Year, P.L. 89-313 Count. Juneau, Alaska. October, 1982.
U.S. Department of the Interior, Bureau of Indian Affairs, Anchorage Office. Data Search. Anchorage, Alaska. May, 1983.

TABLE 9-20

1982-83 SCHOOL YEAR FUNDING FOR SPECIAL EDUCATION STUDENTS IN THE SOUTH CENTRAL REGION

	FY83 Funding Sources					
	Foundation Funding					
School District	Reg. Ed. Allotment	Special Ed. Allotment	Total	P.L. 94-142 Funding	P.L. 89-313 Funding	Total Funding
LEAs						
Anchorage	11,020,015	16,470,600	27,490,615	640,851	214,137	28,345,603
Cordova	316,976	292,902	609,878	10,526		620,404
Kenai	3,198,767	4,263,678	7,462,445	148,738		7,611,183
King Cove	171,923	127,350	299,273	4,659		303,932
Kodiak	1,663,119	1,428,018	3,091,137	63,498		3,154,635
Mat-Su	2,013,111	2,825,472	4,838,583	101,459		4,940,042
Sand Point	37,273	63,675	100,948		3,465	104,413
Unalaska	246,960	191,025	437,985	5,867		443,852
Valdez	708,723	634,621	1,343,344	14,839		1,358,183
REAAs						
Adak	440,222	416,010	856,232		56,133	912,365
Aleutian Chain	336,926	127,350	464,276		12,474	476,750
Chugiak	64,345	50,940	115,285		6,930	122,215
Copper River	423,625	305,640	729,265		9,009	738,274
Pribilof	297,023	191,025	488,048		16,632	504,680
TOTAL	20,939,008	27,388,306	48,327,314	990,437	318,780	49,636,531

Sources: Alaska Department of Education, Division of Education Program Support. FY 1983 P.L. 94-142 and P.L. 89-313 Distribution Calculations, unpublished data. Juneau, Alaska. January, 1983.
Alaska Department of Education, Division of Management, Law, and Finance. Public School Foundation Program Calculations. Juneau, Alaska. March 2, 1983.

In FY 1983, South Central school districts generated over $27 million in special education foundation funds, averaging $4,300 per student. Combined regular education, special education, P.L. 94-142, and P.L. 89-313 funds generated by special education students enrolled in the fourteen school systems totalled just under $50 million (Anchorage's share equalled $28 million), for an average of $7,800 per student. Fifty-two students in the region received specialized outreach/support services from Alaska Resources at an average cost of $5,900 per student. Table 9-20 summarizes special education funding by source.

A combination of special education resources, specialized local programs, itinerant outreach services, specialized State programs, and even funding for out-of-district or out of state placements are available and utilized for handicapped students of South Central Alaska. Out-of-district placements are depicted in Table 9-21.

All programs begin with individual students' needs. School district responses are determined by funding, local availability of special education personnel, commitment of school personnel to plan and provide services, and the interest and commitment of the student's family and other families with handicapped children.

Anchorage is the center of many specialized educational resources and programs. In addition to special programs operated in Anchorage such as the Multi-handicapped Program, the Deaf Program, programs in special schools, facilities, residential treatment centers, and correctional facilities, Anchorage has the most resident specialists. These people are called upon as private consultants by districts across the state.

The state's special education outreach services, Alaska Resources for the Moderately and Severely Impaired, are housed in Anchorage. Specialists in the five program areas - blind/visually impaired, emotionally disturbed, orthopedically handicapped, hearing impaired, and multi-handicapped travel to school districts to provide services. An estimated thirty children might have been placed out-of-home, probably in Anchorage or out of state at a cost per child of $45,000 if ARMSI services had not been available. (Vic Baldwin for the Department of Education, August, 1983.)

Vocational Services

"Vocational services" is the term applied to the activities which assist a person in preparing for, securing, and maintaining employment. Some of the services are geared to school-aged children; others are more appropriate for adults. People with substantial handicaps need the same basic set of career and employment-oriented services as does the general population. The focus and intensity of services provided to people with substantial handicaps may be a bit different from those provided to the general population, but the goal of using these services remains the same--employment.

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TABLE 9-21

SOUTH CENTRAL REGION
1982-83 SCHOOL YEAR OUT-OF-DISTRICT PLACEMENTS

	Level of Home Comm.				Age Range				Exceptionality						Total Placements
Program Placement	I	II	III	IV	3-5	6-12	13-15	16-21	MR	D	SED	OI	SLD	MH	
Anchorage*															
Out of State				9			2	7			6			3	
Jesse Lee Home				1			1				1				
Anchorage Mental Health Program**				7		3	2	2						7	85
State School for the Deaf				36	5	10	9	12		36					
API				16		4	9	3			16				
McLaughlin				16			2	14			3		13		
Mat-Su															
Out of State			2			1	1				2				
Anchorage Mental Health Program			1				1							1	7
State School for the Deaf			2			1		1		2					
API			2			1		1	1		1				
Kenai															
Out of State			2				2				2				
Anchorage Mental Health Program			4			2	2							4	
State School for the Deaf			1		1					1					
McLaughlin			1					1					1		
Kodiak															
State School for the Deaf			1				1			1					2
McLaughlin			1				1						1		
Chugiak															
API	1						1				1				1
Pribilof															
API	1						1				1				1
Unalaska															
Out of State		1				1					1				1
TOTALS	2	1	17	85	6	23	34	42	1	40	34		15	15	105

* = Includes children placed at Anchorage-area contract programs.
** = Only children who are wards of the court; Anchorage School District estimates that an additional 70 children who live with their families in Anchorage are served by this program.

MR = Mentally Retarded	D = Deaf	SED = Seriously Emotionally Disturbed
OI = Orthopedically Impaired	SLD = Specific Learning Disability	MH = Multiply Handicapped

Sources: Alaska Department of Education, Office for Exceptional Children. Juneau, Alaska. March, 1983
Program Surveys, Governor's Council for the Handicapped and Gifted. Fairbanks, Alaska. June, 1983.

Division of Vocational Rehabilitation

The Alaska Division of Vocational Rehabilitation (DVR) is the major vocational agency of State government. DVR is charged under P.L. 93-112 and A.S. 23.15.010 with providing a full range of vocational evaluation, counseling, training, job placement, and follow-along services. These services are available through the office and the Anchorage Evaluation Unit in Anchorage and through branch offices in Kenai and Wasilla. The Kenai office, supervised by the Fairbanks office, serves Kenai, Homer, Seward, and Kodiak. Altogether, the Anchorage, Kenai, and Wasilla offices served 1,019 clients in FY 1982. DVR provides vocational evaluation, counseling, training, placement, and follow-along, in addition to pre-vocational training.

The Anchorage Evaluation Unit conducts vocational evaluations of clients who cannot be served by private facilities. The Unit has two masters-level evaluators, two rehabilitation assistants, and a clerk typist. Its capacity is ten clients.

DVR also conducts pre-vocational evaluations for three or four secondary school students each week for the school districts in Kenai, Kodiak, and Anchorage. Also, DVR funds a part-time vocational counselor to serve the needs of the back pain and rheumatoid arthritis programs at the Alaska Treatment Center. This counselor averages over fifty client contacts per calendar quarter.

Access Alaska

Access Alaska provides pre-vocational and basic skills instruction to developmentally disabled adults. In FY 1983, Access Alaska served forty clients in this way. Also, the agency offers supervision and skills training in food service work for 3-16 developmentally disabled students annually via Anchorage Community College.

Kodiak Aleutian Mental Health Clinic

The Kodiak Aleutian Mental Health Clinic provides pre-vocational training for up to fifteen clients per month. The Kodiak program also offers work evaluations/process assessments of skills and motivational levels, using vocational assessment scales, work samples, and simulated job situations.

This agency provides vocational skills training in remunerative work settings for up to fifteen clients monthly, with both on-site and community job placements. Vocational follow-along consists of training, support, and maintenance in actual job placements, on-the-job work evaluations, and adjustment, with periodic follow-up or shape-up as needed.

Employment and Training Center of Alaska

The Employment and Training Center of Alaska (ETCA) provides functional survival skills training and pre-vocational training, with a capacity of seventy. The agency also conducts vocational evaluations, identifying training needs.

In addition to its pre-vocational and evaluation components, the ETCA offers professional habilitation, rehabilitation, and vocational training services for developmentally disabled and other substantially impaired persons aged 16+. Services include work adjustment and specific skills training in several areas such as food service, janitorial, clerical, and printing/lithographics. The training curriculum for lithographic arts has been approved by the Commission on Post-Secondary Education. ETCA operates a sheltered workshop with a capacity of sixty and competitive job placement for another twenty clients per year. The agency contracts with private and governmental businesses and agencies for production of commercial goods and services. Work adjustment and follow-along services are provided to clients placed in competitive jobs.

Aleutian Pribilof Island Association

The Aleutian Pribilof Island Association provides diagnostic evaluation services through a $23,000 grant from the DVR. The agency also provides vocational counseling and placement services.

Alaska Vocational Services

Alaska Vocational Services provides work adjustment and follow-along for clients placed by the DVR. During FY 1983, the agency served three to four clients per month in Cordova, eight to nine in Palmer/Wasilla, and 35 in Anchorage. The agency is developing semi-sheltered workshops in commercial settings and has a capacity of 25. DVR reimburses Alaska Vocational Services at a rate of $18 per client per day.

Cook Inlet Native Association

The Cook Inlet Native Association trains handicapped adults for employment in clerical positions. In FY 1982, this agency served forty clients with a grant of $44,000.

Alaska Vocational Technical Center

The Alaska Vocational Technical in Seward provides adult basic education and pre-vocational training for the general population, serving 450 people in FY 1982. The Center had a special grant of $20,000 in FY 1982 to train forty handicapped adults in the fast food service industry.

Anchorage Community Mental Health Service

The Anchorage Community Mental Health Service operates a sheltered and semi-sheltered work program for mentally ill DVR clients in the Anchorage area. The agency's FY 1982 grant from DVR was $42,000.

School Districts

The school districts in the South Central Region provide career and vocational education, pre-vocational training, and vocational training as components of the regular school curriculum. The numbers of approved vocational courses offered by each district in the 1982-83 school year were: Adak Region-17; Aleutian Region-13; Anchorage Schools-116; Copper River-41; Cordova City-30; Kenai-79; King Cove-28; Kodiak Island Borough Schools-32; Matanuska-Susitna Borough Schools-97; Pribilof Island-42; Sand Point Schools-13; Unalaska City-30; and, Valdez City-39. These services and courses are provided to all interested students and are not designed especially for the substantially handicapped.

Enabling Services

Case Management Services

Informally, case management functions are carried out by particular agencies currently providing services to a disabled person and his or her family. The agency providing services that the family or person regards as most essential is likely to be asked for guidance, information, and advice by the families and other agencies.

There is no formal case management "system" for people with disabilities, just as there is no such system for the general population or for other population sub-groups. For most services to be provided, however, there are requirements for individual case service planning, development of habilitation, rehabilitation, special education, or family service plans, which is the primary responsibility of the providing agency in consultation and coordination with other related service or health personnel.

Guardianship Services

Guardianship and conservatorship services for people who are disabled can only be provided for legally after following a process of filing a petition and having a hearing in Superior Court. Since guardianship, responsibility for the person and decisions for the person, and conservatorship, management of the person's finances, mean that some or all of the disabled or incapacitated person's legal rights are taken away, special legal proceedings must take place to make sure that rights are not taken away without due process and without basis.

The Third Judicial District includes the South Central Region. Superior Court is located in Anchorage, Kenai, Kodiak and Palmer. Petitions may be filed and heard there. State law provides that a visitor must be appointed to investigate the situation of the person for whom a guardian is sought, to see if guardianship is necessary to protect the individual, and to identify people who might serve as guardian. If the Court determines that guardianship is necessary and that there is no relative or friend to be guardian, the Court can assign the Public Guardian to handle the person's affairs. The public guardian office at the Court System in Anchorage provides information and assistance on guardianship. It serves as guardian or conservator to 79 people.

Staff Training and Manpower Development Services

Each agency has responsibility to provide for staff training. P.L. 94-142 requires training of teachers and other special education personnel. Title VI-B funds are provided to the school district based on special education enrollment and are utilized for training as well as child find activities. The special education outreach program, ARMSI, provides training to local people on an itinerant basis. The Division of Family and Youth Services has a training center in Anchorage for social workers employed by the Division. The Division of Public Health provides health education and training and sets aside money for annual training of infant learning program teachers.

Numerous specialized professional development and training opportunities are available through private agencies, the University, the Community College system, statewide conferences and workshops.

Information and Referral

In the South Central Region information about services and referral to services takes place informally and formally. There are crisis lines, toll free numbers for various agencies, private, municipal state, and federal offices which provide information. Access Alaska has collected service information statewide and is developing a computerized statewide information and referral system for people with disabilities.

Protection and Advocacy Services

Protective services are provided by the Division of Family and Youth Services. Legal services are available on a resident basis in most communities by Alaska Legal Services Corporation and private attorneys. The state Ombudsman's Office in Anchorage accepts and investigates complaints about state agencies.

The agency providing specialized protection and advocacy services to remedy violations of rights or due process, and to seek redress through negotiation, administrative, and legal means, and to provide assistance to disabled individuals who cannot access services themselves, is Protection and Advocacy for the Developmentally Disabled (P.A.D.D.). Fifty-eight people were served by PADD in the South Central Region in FY 1983 for complaints ranging from habilitation and special education to sterilization and inappropriate institutionalization.

Obstacles and Opportunities

Obstacles

Every region has characteristics of geography, economics, population size, attitudes, and values which can present challenges in human service delivery. Many of these obstacles are similar from area to area; others are unique to particular regions or villages. Almost every problem can be overcome through dedication and creativity on the part of community residents. The following obstacles to service delivery for the handicapped have been identified in the South Central Region:

1. The physical environment poses awesome challenges to region wide service systems. The wide dispersal of people, long distances, and difficult travel conditions make it important to develop support competencies at the local level.

2. The South Central Region has no centralized plan for service development. Although the various Native regional corporations adopted tribal specific health plans in 1979, those plans are outdated and were never comprehensive in terms of needs of the disabled. Other plans, such as those by the Municipality of Anchorage and South Central Health Planning and Development, only partially fill the gaps.

3. Lack of services in the past contributed to inappropriate placements of some clients and no services for others. There are now people in residential placements outside of their home communities who could be returned if adequate support services were available. Throughout the region, approximately 96 people need augmented living environments, while only twenty were served in FY 1983. Seventy-seven require devised environments, but only 36 lived in such situations in the region in FY 1983. Yet costs of protective services at Harborview, where a significant number of people are inappropriately placed, were double or triple the costs of augmented and devised services.

4. Some advocates for de-centralizing services in favor of regionalizing specialized services and out-reach programs cite the concentration of specialists in Anchorage as an obstacle to development of skilled people in other areas of the state. Yet Anchorage providers cite needs for more specialists there to handle local Anchorage service demands.

5. In some cases, community residents have attitudes which work against the development of local, community placements for severely disabled people. Positive attitudes and awareness of what can be accomplished locally must precede community acceptance and action.

6. Services to rural areas are fragmented because there are multiple providers and funding sources. The Native regional corporations, the Alaska Public Health Nursing Program, the Indian Health Service, the military, various school districts, non-profit programs, municipalities, and private practitioners all serve the region. While this arrangement usually works well in Anchorage and some of the other larger communities and is desirable in some cases in the rural communities, it can disrupt continuity of care and result in overlapping services or gaps in services for particular villages or individuals within villages.

7. Providers need to develop a functional way for people from different agencies to plan together with individual disabled people and their families. There is no established way of creating a shared sense of a

person's home situation and a shared vision of a person's possibilities. Consequently, responses are more fragmentary than they need to be, and there is less empowerment of existing support networks than is possible. Services developed without a strong sense of a person's context will miss many opportunities.

8. In-home services face numerous obstacles in rural areas. Funding is inadequate for homemaker services and virtually non-existent for home health services. The actual need for in-home services is not known or sufficiently documented in many villages. Training for homemakers and home health aides is poor at best, and trainers are generally unavailable. There is considerable "red tape" involved in obtaining services in many cases, and villages often lack personnel to assist clients with the paperwork. Finally, no agency or organization has yet accepted the responsibility for organization and administration of a system of in-home services for the rural areas.

9. Some augmented and devised environment residential services are expensive compared to those in other regions. This leads to justifications for institutional and nursing home placements, especially since the state may recover 50% of the cost from the federal government.

10. Funding mechanisms tend to follow the program, not the individual or his/her particular needs. This leaves disabled people and their families feeling helpless, without options and without personal control over their lives.

Opportunities

The planning process enables communities to change obstacles into opportunities. Concerned service providers, clients, family members, and other interested people can work together to solve problems and implement community change.

Several opportunities in the area of services for the handicapped are now available in the South Central Region:

1. State law requires the State to plan, develop, and implement a comprehensive system of services and facilities for the handicapped (A.S. 47.80.100). Therefore, the State is obligated to assist the South Central Region to design and implement appropriate services.

2. The lack of a master plan for regional service development creates a favorable climate for innovation in home and family support. If service providers can accept responsibility for planning together, a strong, varied system might be built from the bottom up.

3. Consumer organizations and participation in shaping services are essential. Alaska's legislature has proven responsive to direct expressions of citizen concern for people with handicaps. In particular, parents of people with disabilities and disabled people

themselves are willing to help develop multiple service programs and options.

4. Rural communities should explore the possibility of developing a new role for home and family support specialists. Community health aides have established themselves as a vital service, but their priority is, necessarily, on acute care and care for children. It would take some time for home and family support services to become established in each community, but long term care is becoming more important as communities grow. Developing new competencies for people in small villages would be a further step toward building local skills and career options.

5. All support services workers would benefit from consultation and training to expand the image of what abilities people can develop. The most effective training would come from active participation in individual planning meetings and hands-on assistance from professionals who visit homes along with workers to implement new plans. The region and the various service providers should give particular attention to provision of effective consultation and training services to village workers.

6. The Anchorage area has a wealth of services which serve the entire state and which could provide technical assistance to other regions interested in expanding services. Anchorage service providers could make themselves available for consultation to other regions, just as their services are open to clients from other regions.

7. Programs in Kenai, Mat-Su, and Kodiak have been gaining experience and expertise. Growth patterns, strong local economies, and local agencies ready for new challenges will compete for state funding and add to statewide demands for funds for local services.

8. New agencies and programs in Anchorage such as Access Alaska give new energy and generate fresh approaches to services.

9. Prospects of reductions in state financial support after years of no new money for existing or new programs can stimulate formation of consumer-provider, urban-rural alliances aimed at educating and influencing the executive and legislative branches.

CHAPTER 10

THE SOUTHWEST REGION

Demographics

The Setting

The Southwest Region encompasses the same boundaries as the Bristol Bay Native Association, an area of 40,647 square miles - equivalent to the State of Ohio. (Bristol Bay Area Health Corporation) It is located at the northern end of the Alaska Peninsula, stretching around Bristol Bay, northwest to Goodnews Bay and eastward to Lake Iliamna and Lake Clark. Mountains ring three sides, with the ocean on the fourth.

This region contains over thirty villages scattered along Bristol Bay and Shelikof Strait, as well as around Lake Iliamna and on the Nushagak River. All of the communities have fewer than 550 people, except for Dillingham, a Level III community which serves as the regional center. The Level II communities of Chignik Lake, Iliamna, King Salmon, Naknek, New Stuyahok, and Togiak are subregional centers. (South Central Health Planning and Development, 1982)

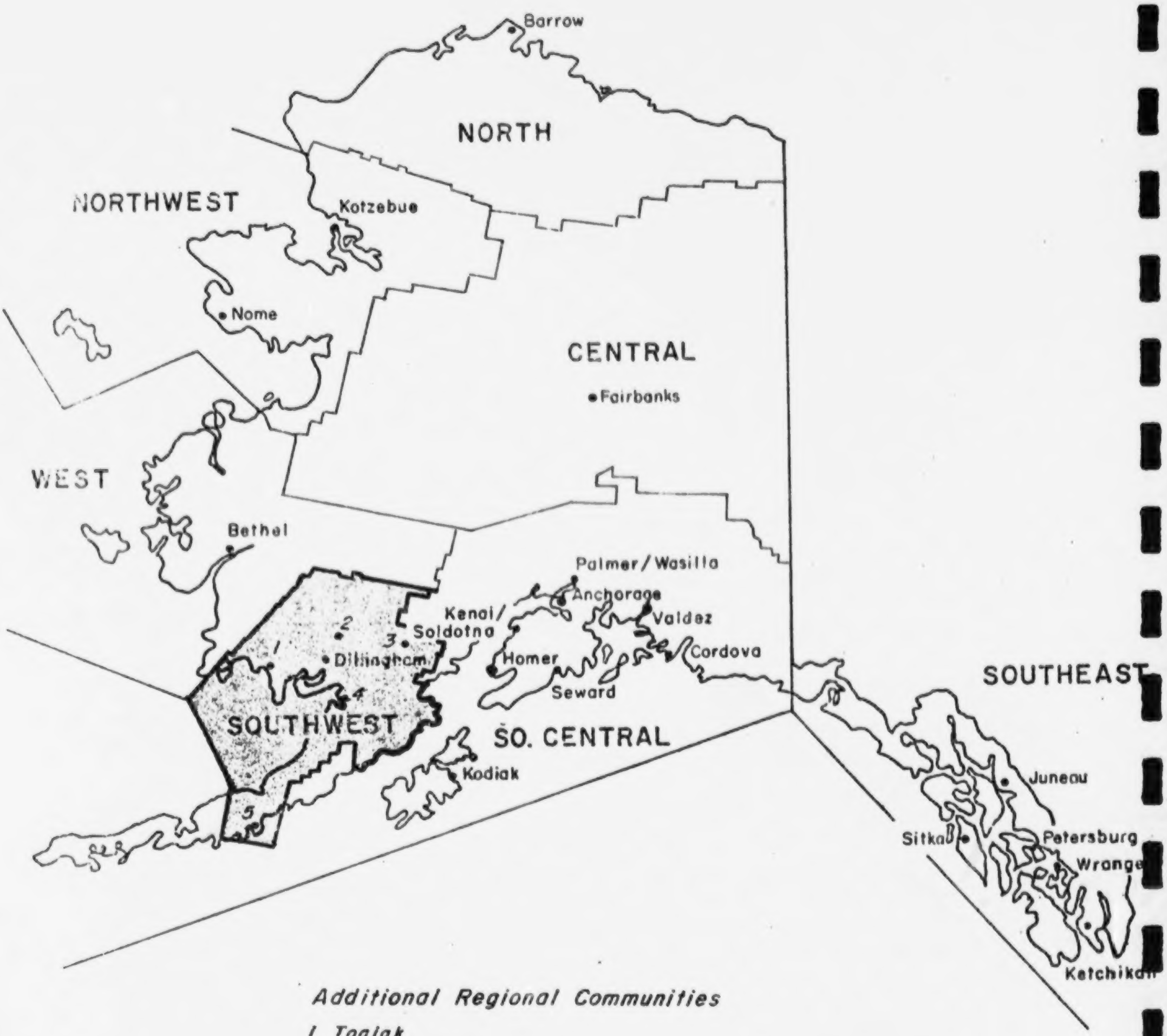
Dillingham and King Salmon are the transportation centers for the region, with most movement being by air or sea. Most of the smaller villages have airstrips situated near water where float planes can land. Weather conditions control the reliability of air and sea access to all of the communities of the area. There are only a few roads in the region, with a total length of less than forty miles. Communications are by RCA or military communications systems or by radio; mail and telegram services are limited.

The Southwest Region's main source of livelihood is the salmon industry, which serves both commercial and subsistence purposes. In the summer commercial season, the population may double, depending upon the expected size of the salmon run. The communities that have canneries attract the bulk of the summer transient population as well as residents from other villages within the region. (Bristol Bay Area Health Corporation)

The People

The population of the Southwest Region was 5,716 in 1981. Alaska Natives, comprised of three different groups, make up about 70% of the total. The lower Peninsula area is populated by people of Aleut descent; the interior villages around Lake Iliamna are Athabaskan; and, the rest of the villages are primarily Yupik Eskimo. (Appel) Approximately 41.8% of the people are children and youth aged 0-20; 3.4% are over the age of 65. Table 10-1 depicts the population of the southwest region by age and subregion. With an average annual growth rate of 1.26%, the region is expected to have 5,932 people by 1984 and 6,221 by 1988, as shown in Table 10-2. (U.S. Department of Commerce, Bureau of the Census)

SOUTHWEST REGION


Barrow
NORTH
NORTHWEST
Kotzebue
Nome
CENTRAL
Fairbanks
WEST
Bethel
Palmer / Wasilla
Anchorage
Kenai/
Soldotna
Valdez
Cordova
Homer
Seward
2
3
1
Dillingham
4
SOUTHWEST
SO. CENTRAL
5
Kodiak
SOUTHEAST
Juneau
Sitka
Petersburg
Wrange
Ketchikan

Additional Regional Communities

1 Toglak
2 New Stuyahok
3 Iliamna
4 King Salmon / Naknek
5 Chignik Lake

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TABLE 10-1

POPULATION OF THE SOUTHWEST REGION, 1980

	Population by Age Group					
Census Area	0-2	3-5	6-20	21-64	65+	Total
Bristol Bay Area	31	34	240	764	25	1,094
Dillingham Area	286	251	1,543	2,367	169	4,616
TOTAL	317	285	1,783	3,131	194	5,710

Source: U.S. Department of Commerce, Bureau of the Census. 1980 Census of Population, General Population Characteristics, Part 3, Alaska. PC80-1-B3 Alaska. Washington, D.C. August, 1982. Pp. 3-56, 3-57.

The Economy and Culture

Median family incomes in the Southwest Region are about 60% below the average for the state as a whole. The income and employment patterns of the non-Native residents resemble those of residents statewide, except that there is a larger proportion in the lower income categories. For Natives, participation in wage and salary employment is low, and incomes of Native families is very low. The median income for Natives in the southwest region is less than half of the statewide median for all families and is considerably below the statewide average for non-white families. One-sixth of the families receive public assistance - three times the statewide average. Ninety-six percent of the families receiving assistance are Native. (South Central Health Planning and Development, 1982)

Fishing is the primary occupation of the region, with good harvests of salmon and shellfish annually. There are quantities of marine and land mammals in the area as well, many of which are taken for subsistence purposes. Government is the largest wage and salary employer, accounting for 40% of the jobs. (South Central Health Planning and Development, 1982)

Social Problems

The tremendous social problems of alcoholism, suicide, mental illness, domestic violence, and crime are heightened in the Southwest Region by widespread poverty and unemployment. The cycle of poverty, including depression, child abuse and neglect, low self-esteem, alcoholism, and dependence on public assistance, is likely to continue as long as the economy remains limited. (Bristol Bay Area Health Corporation)

The Target Population

As described in Chapter 5, all children who are substantially handicapped are considered to be developmentally disabled. These people make up about 3% of the age groups 0-2 and 3-5 and 1.87% aged 6-20. Adults are counted among the developmentally disabled only if their impairments arose in childhood. On the average, 1.49% of the population aged 21-64 and .5% aged 65+ are developmentally disabled. In addition, about 1.9% of the people aged 21-64 and 10% aged 65+ have other substantial limitations.

Table 10-3 summarizes the number of Southwest Region residents with substantial disabilities. Altogether, there were approximately 100 developmentally disabled and 78 otherwise disabled people in the southwest region in 1980. By 1988, those numbers are expected to rise to 107 and 86, respectively. Around 45 will be among the school-aged (3-20) population. Table 10-4 estimates numbers of substantially disabled people by age group for 1984 and 1988.

TABLE 10-2

POPULATION OF THE SOUTHWEST REGION BY AGE GROUP,
1980 AND PROJECTED TO 1984 and 1988

Age Group	1980	1984	1988
0-2	317	329	345
3-5	285	296	310
6-20	1,783	1,853	1,943
21-64	3,131	3,253	3,411
65+	194	202	212
TOTAL	5,710	5,932	6,221

Source: U.S. Department of Commerce, Bureau of the Census. 1980 Census of Population, General Population Characteristics, Part 3, Alaska. PC80-1-B3 Alaska. Washington, D.C. August, 1982. Pp. 3-56, 3-57.

TABLE 10-3

SOUTHWEST REGION ESTIMATED POPULATION OF PERSONS WITH SUBSTANTIAL HANDICAPS, 1980

	Persons with Substantial Handicaps		
Age Group	Developmentally Disabled	Other	Total
0-2	10	0	10
3-5	9	0	9
6-20	33	0	33
21-64	47	59	106
65+	1	19	20
TOTAL	100	78	178

TABLE 10-4

SOUTHWEST REGION, ESTIMATED SUBSTANTIALLY DISABLED* POPULATION BY AGE, 1980 and PROJECTED TO 1984 and 1988

	Substantially Disabled* Population		
Age Group	1980	1984	1988
0-2	10	10	10
3-5	9	9	9
6-20	33	35	36
21-64	106	111	116
65+	20	21	22
TOTAL	178	186	193

* Includes both developmentally disabled and other disabled people.

Sources: U.S. Department of Commerce, Bureau of the Census. 1980 Census of Population, General Population Characteristics, Part 3, Alaska. Washington, D.C. August, 1982. Pp. 3-56, 3-57.

Governor's Council for the Handicapped and Gifted. 1981-83 Alaska Developmental Disabilities State Plan. Fairbanks, Alaska. August, 1980. Pp. 25-29.

Urban Institute. Report of the Comprehensive Service Needs Study. DHEW-RSA. June, 1975. Pp. 57-58, 72.

Older Alaskans Commission. Phone interview with Lawry Robertson. January, 1983.

Methodology: See Appendix.

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Community Descriptions

Regional Center

Dillingham, a Level III community, is the major service, transportation, and communications center for the Southwest Region. As of July 1, 1981, Dillingham's population was 1,670. At that time, the community was 57% Native; among the Native population, the median age was 21.4; 23.54% of the population was under eighteen years old. (U.S. Department of Commerce, Bureau of the Census)

Dillingham is the headquarters for the Bristol Bay Area Health Corporation and the Bristol Bay Native Corporation. As a first class city, Dillingham runs the Dillingham City School System and is home to the Bristol Bay Area Hospital.

Bristol Bay Area Subregions

Geography and settlement practices have suggested a subregional development pattern within the Southwest Region. Although not joined by roads in the usual "cluster-and-hub" pattern, these subregions function in much the same way, with the small villages looking to the slightly larger subregional centers for services. The communities remain more autonomous, however, and are classified by level. Each of the six subregions of the Southwest Region is sketched below. Table 10-5 summarizes the 1980 populations of the villages by subregion.

Alaska Peninsula Subregion

The Alaska Peninsula subregion is located on the Peninsula between Strogonof Point and the Muddy River on the north and between Kujulik Bay and Stepovak Bay on the south. It contains the Level I villages of Chignik, Chignik Lagoon, Ivanof Bay, and Perryville. Chignik Lake, a Level II community, serves as the subregional center. All of the villages are situated on the southern side of Peninsula on the Pacific coast.

Iliamna Lake Subregion

The Iliamna Lake subregion contains the five villages bordering Iliamna Lake, as well as Nondalton on the river north of Newhalen. Iliamna, a Level II community, is the subregional center. Igiugig and Iliamna have airports, and Nondalton is linked with Iliamna via road.

Kvichak Bay Subregion

The Kvichak Bay subregion's seven villages stretch from Levelock, above Kvichak Bay on the Kvichak River, to Port Heiden on the northern coast of the Alaska Peninsula. King Salmon, a Level II community, is recognized as the subregional center. Naknek, down the Naknek River from King Salmon and on the Kvichak Bay, is also a Level II community. King Salmon and Naknek are

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sometimes considered together as the subregional center. Other villages in the subregion are Egegik, Pilot Point, and Ugashik.

Nushagak Bay Subregion

Dillingham, the regional center and a Level III community, also serves as the subregional center for the Nushagak Bay subregion. In addition to Dillingham, the area includes Clark's Point and Ekuk on Nushagak Bay, Aleknagik north of Dillingham on the Wood River, and Manokotak near Amanka Lake. The small settlements of Igushik, Konakanak, Nushagak, and Wood River are also part of this subregion.

Nushagak River Subregion

The Nushagak River subregion includes the four villages located inland from Nushagak Bay on the Nushagak River. New Stuyahok, a Level II community, is the subregional center. Ekwok, Koliganek, and Portage Creek are Level I villages.

Togiak Bay Subregion

The Togiak Bay subregion consists of Togiak, a Level II community and the subregional center, and Twin Hills, just northeast of Togiak. Although technically outside of the Dillingham census area and, therefore, the southwest region, Platinum and Goodnews on Goodnews Bay are sometimes considered part of the Togiak Bay subregion.

Service Flow Patterns

The vast majority of the services for the Southwest Region are centered in Dillingham, with King Salmon as a secondary center. People go to Dillingham for inpatient care at the Bristol Bay Area Hospital, and itinerant services from the Public Health Service and the Bristol Bay Area Health Corporation radiate from Dillingham. As in most regions, the flow is from Level I communities to subregional centers, then to the regional center, and finally to Anchorage for specialized services.

Available Services

Health Services

The primary health service provider in the Southwest Region is the Bristol Bay Area Health Corporation. A private, non-profit Native organization, the Corporation operates on grants and contracts with the State of Alaska and the Indian Health Service. The Corporation offers a wide range of services, including family medicine, dental care, mental health care, and alcoholism treatment services.

TABLE 10-5

POPULATION OF THE SOUTHWEST REGION BY VILLAGE, WITH COMMUNITY LEVELS, 1980

Village	Community Level	Population
Alaska Peninsula Subregion		
Chignik	I	178
Chignik Lagoon	I	48
Chignik Lake	II	138
Ivanof Bay	I	40
Perryville	I	111
Iliamna Lake Subregion		
Igiugig	I	33
Iliamna	II	94
Kokhanok	I	83
Newhalen	I	87
Nondalton	I	173
Pedro Bay	I	33
Kvichak Bay Subregion		
Egegik	I	75
King Salmon	II	545
Levelock	I	79
Naknek	II	318
Pilot Point	I	66
Port Heiden	I	92
South Naknek	I	145
Ugashik	I	13
Nushagak Bay Subregion		
Aleknagik	I	154
Clark's Point	I	79
Dillingham	III	1,563
Ekuk	I	7*
Manokotak	I	294
Nushagak River Subregion		
Ekwok	I	77
Koliganek	I	117
New Stuyahok	II	331
Portage Creek	I	48
Togiak Bay Subregion		
Togiak	II	470
Twin Hills	I	70
Unassigned	--	149
TOTAL	--	5,710

* The population of Ekuk increases to around 1,000 during fishing season.

Sources: Alaska Department of Labor. Alaska Population Overview 1981. Juneau, Alaska. 1982. p. 16.
South Central Health Planning and Development. Health Systems Plan 1982-1986. Anchorage, Alaska. 1982. Pp. 135, 137.

The Bristol Bay Area Hospital, formerly the Kanakanak PHS Hospital, is located at Kanakanak, seven miles from Dillingham, and has 28 beds. Medical services are provided by two physicians and one physician assistant. The medical staff provide emergency room care, primary and secondary outpatient and inpatient services, and normal obstetrical care. While emergency procedures are performed, all patients in need of surgery are transferred to the Alaska Native Medical Center or to private hospitals and physicians in Anchorage.

Physician specialists come from Anchorage to offer outpatient services periodically throughout the year. Also, physician services are made available to village residents through daily medical radio traffic with the health aide and through annual field visits. While in the villages, physicians work with the health aides, see people with chronic and acute illnesses, and, whenever possible, present health education material. Ancillary services through the hospital include radiology, laboratory, and pharmacy.

General dental services are offered at Kanakanak and in the villages during field visits. At Kanakanak, the Bristol Bay Area Health Corporation provides dentures and other dental appliances to Native beneficiaries for the cost of lab fees and a percentage of the cost of operations. Patients with extensive treatment needs are referred to the private sector.

The Bay and Peninsula Clinic, at King Salmon, is staffed by mid-level practitioners. This clinic is supported by the Bristol Bay Borough. The Bristol Bay Borough is also building a new clinic in Naknek, fifteen miles from the Bay and Peninsula Clinic.

The Bristol Bay Area Health Corporation's community health aide program provides primary health care in thirty villages. The medical staff at the hospital in Kanakanak supervises the care of the health aides through annual visits to villages and daily verbal contact during medical traffic via short wave radio or telephones. At other times, the health aides provide acute and preventive health care utilizing protocols from the Health Aide Manual. All but two villages served by the health aide program have a clinic or are in the process of constructing one.

Other health-related services provided through the Bristol Bay Area Health Corporation are emergency medical services; alcohol treatment services; the alcohol safety action program; mental health services; environmental health services; and the community injury control program.

The only other significant provider of health services in the region is the State of Alaska Division of Public Health, which provides itinerant public health nursing services throughout the area.

Table 10-6 summarizes the health services available in the Southwest Region. (Bristol Bay Area Health Corporation)

Support Services

Support services are those services which are needed in addition to adequate medical care, educational and vocational services, and employment opportunities in order for a substantially handicapped person to live independently or with his/her family. There are three major types of support services--maintenance services, living skills training services, and material support services.

Maintenance Services

The Southwest Region lacks most services which are commonly considered "maintenance" services except on an informal basis. There is no day care assistance program in the Region and no licensed day care providers. Respite care, for which approximately eight families have a need, is unavailable.

Homemaker services provide household assistance, chore services, and/or non-medical personal assistance to enable a person and his/her family to live at home. The Alaska Division of Family and Youth Services contracts with Alaska Management Technologies to provide homemaker services statewide. However, in the Southwest Region, these services are available only in Dillingham and Iliamna. During FY 1983, approximately ninety individuals were served at a total cost of $117,690. Each person received an average of 107.2 hours of service at an annual cost per client of $1,308. The proportion of these clients who were substantially handicapped is unknown.

Home health aide, home health nursing, and personal aide and attendant services do not exist in the Southwest Region. Transportation services are not provided other than by the school districts on an as-needed basis. Recreational opportunities are minimal, and no special services are available for handicapped people other than through the school's special education programs and the Special Olympics.

Developmental Services

There are no special developmental training programs available in the Southwest Region other than activities through the school districts' special education program. Some training takes place informally through the community health aides, public health nurses, and others.

Material Support Services

Cash assistance is available for individuals and families in the Southwest Region on the same basis as elsewhere in the state. The major categories of special assistance to the handicapped are Aid to the Disabled and Aid to the Blind, through the State's Division of Public Assistance, and Supplemental Security Income (SSI) payments, in accordance with the federal Social Security Act.

Personal adaptive equipment is provided to disabled children through Alaska's Handicapped Children's Program. Personal adaptive equipment for adults and environmental adaptive equipment for people of all ages are generally unavailable except through private or third-party payment or on informal bases.

TABLE 10-6

HEALTH SERVICES AVAILABLE IN THE NORTHERN REGION OF ALASKA, by COMMUNITY, 1983

			Prevention				Early Identification											
Community	Level	PC	SHE	PA	WCP	I	PNT	MDS	VHS	MTS	D&E	MS	DS	OT	PT	SSH	HHN	HHA
Alaska Peninsula Subregion																		
Chignik	I	L			L	L		I	I			I	I					
Chignik Lagoon	I	L			L	L		I	I			I	I					
Chignik Lake	II	L	L		L	L		I	I			I	I					
Ivanof Bay	I	L			L	L		I	I			I	I					
Perryville	I	L			L	L												
Iliamna Lake Subregion																		
Igiugig	I	L			L	L		I	I			I	I					
Iliamna	II	L	L		L	L												
Kokhanok	I	L			L	L		I	I			I	I					
Newhalen	I	L			L	L		I	I			I	I					
Nondalton	I	L			L	L		I	I			I	I					
Pedro Bay	I	L			L	L		I	I			I	I					
Kvichak Bay Subregion																		
Egegik	I	L			L	L		I	I			I	I					
King Salmon	II	L	L		L	L		I	I			I	I					
Lavelock	I	L			L	L		I	I			I	I					
Naknek	II	L	L		L	L		L	L			I	I					
Pilot Point	I	L			L	L		I	I			I	I					
Port Heiden	I	L			L	L		I	I			I	I					
South Naknek	I	L			L	L		I	I			I	I					
Ugashik	I																	
Nushagak Bay Subregion																		
Aleknagik	I	L			L	L		I	I			I	I					
Clark's Point	I	L			L	L		I	I			I	I					
Dillingham	III	L	L		L	L	L	L	L	L	L	L	L					
Ekuk	I	L			L	L												
Manokotak	I	L			L	L		I	I			I	I					
Nushagak River Subregion																		
Ekwok	I	L			L	L		I	I			I	I					
Koliganek	I	L			L	L		I	I			I	I					
New Stuyahok	II	L	L		L	L		I	I			I	I					
Portage Creek	I	L			L	L		I	I			I	I					
Togiak Bay Subregion																		
Togiak	II	L	L		L	L		I	I			I	I					
Twin Hills	I	L			L	L		I	I			I	I					

I = itinerant L = locally-based

PC = Prenatal care
SHE = School health education
PA = Public awareness
WCP = Well-child program
I = Immunizations
PNT = Prenatal Testing

MDS = Medical/developmental screening
VHS = Vision and hearing screening
MTS = Metabolic screening
D&E = Diagnosis and evaluation of handicapping conditions
MS = Medical services

DS = Dental services
OT = Occupational therapy
PT = Physical therapy
SSH = Speech and hearing services
HHN = Home health nursing
HHA = Home health aide services

Sources: South Central Health Planning and Development. Health Systems Plan 1982-1986. Anchorage, Alaska. 1982.
Bristol Bay Area Health Corporation. 1982 Annual Report. Dillingham, Alaska. 1982.

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Residential Services

Services Available in the Southwest Region

Almost all of the developmentally disabled people from the Southwest Region live within their communities in natural environments. The region itself lacks all forms of residential options except for foster care provided by the Division of Family and Youth Services.

During FY 1983, there was one substantially disabled child in foster care in the Southwest Region. This child was not so severely impaired that he required specialized foster care, but he did need placement outside of his natural family. This particular individual considered the South Central Region to be his home region.

Facilities Utilized by Residents of the Southwest Region

During FY 1983, seven substantially disabled people from the Southwest Region received residential care outside of their home communities. One young person received augmented services in a DFYS foster home placement. Two were in devised environments--one in Anchorage at the Hope Cottages Adult Group Home and one at the Gateway Opportunity Center Group Home in Ketchikan. There was also one person in each of the following protective environments: Nakoyia Health Care Center in Anchorage; Careage North in Fairbanks; Harborview Developmental Center in Valdez; and, Hope Cottages ICF-MR in Anchorage.

Table 10-7 summarizes residential placements of Southwest Region residents during FY 1983.

Residential Service Needs of Southwest Region Residents

Because of the small population of the Southwest Region, there can be considerable random variation in service needs. This fluctuation sometimes results in projections of need which are lower than the numbers of people receiving service. In these cases, it is impossible to tell without individual functional assessments whether persons are inappropriately placed or whether they are in fact well placed but were simply uncounted by the prediction method. The assessments which have been undertaken for Alaskan residents, while not highly scientific at this point, seem to indicate that there has been a tendency to place disabled persons in higher levels of care than their conditions might warrant. This problem is particularly noticeable for residents of rural regions.

In the Southwest Region, as Table 10-8 shows, approximately ten individuals need some sort of residential assistance, be it augmented, devised, or protective. Four require augmented environments, but only one person is placed in such a situation. Three need protective environments, but four are so placed. It would appear that two people from the Region are placed in residential settings which provide care beyond their degree of need, whereas five people remain without service.

TABLE 10-7

RESIDENTIAL PLACEMENTS OF SOUTHWEST REGION RESIDENTS WITH SUBSTANTIAL HANDICAPS, FY 1983

Program by Type of Environment	Location	Number of Residents by Age Group				
		0-5	6-20	21-64	65+	Total
AUGMENTED						
DFYS Foster Care	Statewide	0	1	0	0	1
DEVISED						
Gateway Opportunity Center Group Homes	Ketchikan	0	0	1	0	1
Hope Cottages Adult Group Homes	Anchorage	0	1	0	0	1
PROTECTIVE						
Careage North	Fairbanks	0	0	1	0	1
Harborview Developmental Center	Valdez	0	0	1	0	1
Hope Cottages ICF-MR	Anchorage	0	1	0	0	1
Nakoyia Health Care Center	Anchorage	0	0	1	0	1
TOTAL		0	3	4	0	7

Source: Governor's Council for the Handicapped and Gifted. Survey of Provider Agencies, January - June, 1983. Fairbanks, Alaska. July, 1983.

TABLE 10-8

NUMBERS OF SUBSTANTIALLY HANDICAPPED PERSONS NEEDING AND RECEIVING RESIDENTIAL PLACEMENTS SOUTHWEST REGION, 1983

	Number of People				
Placement by Age Group	Needing Service	Receiving Service in Home Region	Receiving Service Outside Home Region	Unserved	Unserved in Home Region
AUGMENTED ENVIRONMENT					
0-5	1	0	0	1	1
6-20	1	0	1	0	1
21+	2	0	0	2	2
All ages	4	0	1	3	4
DEVISED ENVIRONMENT					
0-5	1	0	0	1	1
6-20	1	0	1	0	1
21+	1	0	1	0	1
All ages	3	0	2	1	3
PROTECTIVE ENVIRONMENT					
0-5	1	0	0	1	1
6-20	1	0	1	0	1
21+	1	0	3*	[2]	1
All ages	3	0	4*	[1]	3
TOTAL	10	0	7*	3	10

* More people are placed in protective environments than would appear to need such care.
[] Number of people considered to be "over-placed" or not in need of protective placement.

Source: Governor's Council for the Handicapped and Gifted, FY 81-82 DD State Plan. Fairbanks, Alaska. Chapter 6.
Surveys of provider agencies. January, 1983.
Analysis of special education and residential placement data. June, 1983.

Costs of Residential Services Provided in the Southwest Region

The only residential service routinely provided within the Southwest Region is DFYS foster care, an augmented environment. In FY 1983, $5,212 was budgeted from the State General Fund to pay for DFYS foster care services within the Region, at an average daily cost per recipient of $14.28.

Educational Services

Infant Learning Program

Early education and infant learning services for infants and children under the age of three are provided by Bristol Bay Native Association, a regional health corporation organized under the Alaska Native Claims Settlement Act. Bristol Bay Native Association provides most of the health and social services in the region, in conjunction with the Alaska Native Health Services and the State of Alaska Department of Health and Social Services. The Infant Learning Program is one of the newer components of the agency, added in November 1981, following initiation of services the previous year by the Bristol Bay Regional Resource Center based in Anchorage.

Babies born with handicaps and young children who are "at risk" of becoming handicapped or disabled are screened by the program teacher, and their parents are provided with home-based help to stimulate development and overcome or adapt to various handicapping conditions. The program services are offered year-round, free of charge. The major goal of the program is to "train parents to utilize their talents as primary facilitators in their infant's progress towards a near-normal developmental pattern." As the program narrative states, parents are with their infants all of the time, and no teacher can take the place of the parents. Therefore, the parents are the natural service providers. The program staff help the parents learn and use new skills and knowledge to foster their children's development.

In 1982, the program identified and served eight children in the Infant Learning Program in six of the thirty villages in the region. Services were provided by a teacher-coordinator based in Dillingham who made monthly or bimonthly visits to the children in their homes.

Not all infants in need of services have been identified. The Council estimates that sixteen children will need the services. Bristol Bay Native Association recognizes that,

> "It takes time for a program like this to establish itself in a region where the local people have seen service providers come, make promises, then disappear, never to be seen again. The Program must establish itself as reliable and with good services provided. Parents must learn to recognize developmental delays and realize that delayed development, no matter what the cause, can be diagnosed and worked with. When the Program has accomplished some reliability and when parents have been educated to recognize delays, local people will be more receptive to enrolling their infants in the program and seeking

help and support. In the meanwhile, the Program must be advertised and Child Find activities conducted throughout the region."

Recognizing the difficulties of providing frequent enough services to the families in the different villages, the Program plans to hire two village health aides to work with the teacher starting in the summer of 1983. The aides will be in Naknek and New Stuyahok and will make weekly home visits of about an hour each. With the teacher-coordinator in Dillingham, three of the six Bristol Bay sub-regions will have Infant Learning Program staff as follows:

Community	Subregion	Level	Designation
Dillingham	Nushagak Bay	III	Regional Center
Naknek	Kvichak Bay	II	Subregional Center
Stuyahok	Nushagak River	II	Subregional Center

Program funding is expected to be $73,000 from the Division of Public Health for FY 1984.

TABLE 10-9

SOUTHWEST REGION
INFANT LEARNING PROGRAM ENROLLMENT STATISTICS, FY 1982

		Total Pop. 0-2	Disabled Children				ILP Utilization				Funding (in thousands)		
Community	Agency	FY80	At Risk	DD	Screened Svd	Enrolled	T	MDE	Contact Hours	Number Home Visits	FY82	FY83	FY84
Bristol Bay/ Dillingham	Bristol Bay Native Association	317	16	9	12	12	4	3	156	22	62.4	87.5	73.0

DD = developmentally delayed; T = terminated; MDE = received multi-disciplinary evaluations.

Sources: Division of Public Health, Infant Learning Program Year-End Report, FY82. Anchorage, Alaska. September, 1982
Division of Public Health, FY84 budget allocations, Infant Learning Program Coordinator. Anchorage, Alaska. August, 1982.

Pre-School

There are no Head Start Programs in the Southwest Region. Dillingham City Schools reported four handicapped children aged 3-5 in their P.L. 94-142 Title VI-B Child Count data in December 1982. Three children were classified as speech impaired and one as learning disabled.

TABLE 10-10

1982-83 SCHOOL YEAR FUNDING FOR SPECIAL EDUCATION PUBLIC SCHOOLS
SOUTHWEST REGION

	FY83 Funding Sources					
	Foundation Funding					
School District	Reg. Ed. Allotment	Special Ed. Allotment	Total	P.L. 94-142 Funding	P.L. 89-313 Funding	Total Funding
LEAs						
Bristol Bay	135,354	131,594	266,948	3,106		270,054
Dillingham	273,691	263,188	536,879	8,110		544,989
REAAs						
Lake & Peninsula	564,364	197,391	761,755		26,334	788,089
Southwest Region	749,486	394,782	1,139,268		38,115	1,177,383
TOTAL	1,717,895	986,955	2,704,850	11,216	64,449	2,780,515

Sources: Alaska Department of Education, Division of Education Program Support. FY 1983 P.L. 94-142 and P.L. 89-313 Distribution Calculations, unpublished data. Juneau, Alaska. January, 1983.
Alaska Department of Education, Division of Management, Law, and Finance. Public School Foundation Program Calculations. Juneau, Alaska. March 2, 1983.

TABLE 10-11

1982-83 SPECIAL EDUCATION ENROLLMENT INFORMATION
SOUTHWEST REGION

					Exceptionality											
School District	Number of Schools	Total Enrollment	Number of Sp Ed Students	% of Total Enrollment	MR	HH	D	SI	VH	SED	OI	OHI	SLD	DB	MH	Out of District
LEAs																
Bristol Bay	3	250	18	7				4					14			1
Dillingham	2	378	47	12	3			9			1		30		4	
REAAs																
Lake Peninsula	14	349	38	11	3			16					19			
SW Region	11	532	55	10	5	5		8			1		35		1	
TOTAL		1,509	158	10**	11	5	0	37	0	0	2	0	98	0	5	1

MR = Mentally Retarded
HH = Hard of Hearing
D = Deaf
SI = Speech Impaired
VH = Visually Handicapped
SED = Seriously Emotionally Disturbed
OI = Orthopedically Impaired
OHI = Other Health Impaired
SLD = Specific Learning Disability
DB = Deaf/Blind
MH = Multiply Handicapped

Sources: Alaska Department of Education. 1982-83 School Year, P.L. 94-142 Count. Juneau, Alaska. December, 1982.
Alaska Department of Education. 1982-83 School Year, P.L. 89-313 Count. Juneau, Alaska. October, 1982.
U.S. Department of the Interior, Bureau of Indian Affairs, Anchorage Office - Data Search. Anchorage, Alaska. May, 1983.

Bristol Bay School District reported one speech impaired pre-schooler in December 1982. None are reported from the Lake and Peninsula REAA. The total pre-school, age 3-5 population, is just under 300 children, slightly less than the number of children under age 3. The Infant Learning Program reported 12 children enrolled, or 3% of the 0-2 population. The schools reported 158 special education students, 10% of the total school population. One would therefore expect to find between eleven and twenty-eight pre-school handicapped children in the region.

Special Education

Of the 1,509 students in school in the Southwest Region in 1982-83, 158 received special education services. Percentage of students in special education ranged from a low of 7% in Bristol Bay to a high of 12% in Dillingham City Schools. Two-thirds of the total were learning disabled, one-fourth were speech impaired, and the remaining 15% were classified mentally retarded (11), hard of hearing (5), orthopedically impaired (2) or multi-handicapped (5). All of the hard of hearing students were from the Southwest REAA and four of the five multi-handicapped students were in Dillingham schools. These school systems used the Alaska Resource (ARMSI) outreach services as well as private specialists to provide testing, evaluation, therapeutic, and specialized program services for their special education students.

Only one student, who was over age 16 and from a Level II community, was served outside the region at the Anchorage School District Multi-Handicapped Program.

Vocational Services

"Vocational services" is the term applied to the activities which assist a person in preparing for, securing, and maintaining employment. Some of the services are geared to school-aged children; others are more appropriate for adults. People with substantial handicaps need the same basic set of career and employment-oriented services as does the general population. The focus and intensity of services provided to people with substantial handicaps may be a bit different from those provided to the general population, but the goal of using these services remains the same--employment.

The only vocational services provided in the Southwest Region are those offered through the school districts. These districts provide career and vocational education, pre-vocational training, and vocational training as components of the regular school curriculum. The numbers of approved vocational courses offered by each district in the 1982-83 school year were: Bristol Bay Borough-22; Dillingham-93; Lake and Peninsula-52; and, Southwest Region-25. These services and courses are provided to all interested students and are not designed especially for the substantially handicapped.

Enabling Services

Case Management Services

Informally, case management functions are carried out by particular agencies currently providing services to a disabled person and his or her family. For families involved in the Infant Learning Program, for example, the teacher is looked to for guidance, information, and advice by the families and other agencies. The teacher may also assist, with family approval, in making referrals, planning, and obtaining, other needed services. Community health aides are the local, resident village health professionals who also serve this function for many, also on an informal basis as an adjunct to health care responsibilities. Division of Family and Youth Services Social Workers also assist in case management as part of their provision of protective or other family services.

There is no formal case management "system" for people with disabilities, just as there is no such system for the general population or for other population sub-groups. For most services to be provided, however, there are requirements for individual case service planning, development of habilitation, rehabilitation, special education, or family service plans, which is the primary responsibility of the providing agency in consultation and coordination with other related service or health personnel.

Guardianship Services

Guardianship and conservatorship services for people who are disabled can only be provided for legally after following a process of filing a petition and having a hearing in Superior Court. Since guardianship, responsibility for the person and decisions for the person, and conservatorship, management of the person's finances, mean that some or all of the disabled or incapacitated person's legal rights are taken away, special legal proceedings must take place to make sure that rights are not taken away without due process and without basis.

The Fourth Judicial District includes the South West Region. A Superior Court Judge is at Bethel and petitions may be filed and heard there or at Dillingham, when court is held there. State law provides that a visitor must be appointed to investigate the situation of the person for whom a guardian is sought, to see if guardianship is necessary to protect the individual, and to identify people who might serve as guardian. If the Court determines that guardianship is necessary and that there is no relative or friend to be guardian, the Court can assign the Public Guardian to handle the person's affairs.

Staff Training and Manpower Development Services

P.L. 94-142 requires training of teachers and other special education personnel. Title VI-B funds are provided to the school district based on special education enrollment and are utilized for training as well as child find activities. The special education outreach program, ARMSI, provides training to local people on an itinerant basis. The Division of Family and Youth Services has a training center in Anchorage for social workers employed by the Division. The Division of Public Health provides health education and training and sets aside money for annual training of infant learning program teachers.

The Public Health Service assists Bristol Bay Area Health Corporation in training village health aides and, through the Kanakanuk hospital staff, provides an important training resource in the region.

Information and Referral

In the Southwest Region information about services and referral to services takes place informally and formally. Because of the small number of people living in villages and in Dillingham word gets around fast about new services, new workers, and about people's impressions and perceptions of service delivery. Each service provider has a portion of the over-all responsibility to explain services, answer questions, make referrals, and coordinate with other workers and people in the community. A great deal of coordination is required because of the use of itinerant services. This means that local people must plan and coordinate schedules, trips, flights, and meetings between people in the villages such as the health aides as well as with itinerant providers who may be coming from Anchorage or beyond. At this point in time there is no over-all coordination of health and social services information and referral.

Protection and Advocacy Services

Protective services are provided by the Division of Family and Youth Services. Legal services are available on a resident basis in Dillingham and on an itinerant basis to the villages by Alaska Legal Services Corporation. The state Ombudsman's Office in Anchorage accepts and investigates complaints about state agencies and provides itinerant service to Dillingham if necessary.

The only agency providing specialized protection and advocacy services to remedy violations of rights or due process, and to seek redress through negotiation, administrative, and legal means, and to provide assistance to disabled individuals who cannot access services themselves, is Protection and Advocacy for the Developmentally Disabled (P.A.D.D.). An advocate in Anchorage can receive inquiries and provide services to the region on an itinerant basis. Two children with disabilities in the Southwest Region received assistance from PADD in FY 1983.

Obstacles and Opportunities

Obstacles

Every region has characteristics of geography, economics, population size, attitudes, and values which can present challenges in human service delivery. Many of these obstacles are similar from area to area; others are unique to particular regions, or villages. Almost every problem can be overcome through dedication and creativity on the part of community residents. The following obstacles to service delivery for the handicapped have been identified in the Southwest Region:

1. The physical environment poses awesome challenges to regionwide service systems. The wide dispersal of people, long distances, and difficult travel conditions make it important to develop support competencies at the local level.

2. The small population size of the Southwest Region, particularly outside of Dillingham, causes the provision of certain kinds of services not to be feasible. There are not enough clients to share overhead costs, nor can providers maintain their technical skills with so few people to serve.

3. Pervasive poverty, especially among Native residents, restricts the service options which can be developed at the local level. Many people cannot contribute anything toward fees for service.

4. Lack of services in the past contributed to inappropriate placements of some clients and no services for others. There are now people in residential placements outside of their home communities who could be returned if adequate support services were available. Community services are needed, especially placements in augmented environments and support services.

5. In some cases, community residents have attitudes which work against the development of local, community placements for severely disabled people. Positive attitudes and awareness of what can be accomplished locally must precede community acceptance and action.

6. In-home services face numerous obstacles in rural areas. Funding is inadequate for homemaker services, which are offered only in Dillingham and Iliamna, and non-existent for home health services. The actual need for in-home services is not known or sufficiently documented in many villages. Training for homemakers and home health aides is needed, and trainers are generally unavailable. There is considerable "red tape" involved in obtaining services in many cases, and villages often lack personnel to assist clients with the paperwork. Finally, no agency or organization has yet accepted the responsibility for organization and administration of a system of in-home services for the rural areas.

Opportunities

The planning process enables communities to change obstacles into opportunities. Concerned service providers, clients, family members, and other interested people can work together to solve problems and implement community change.

Several opportunities in the area of services for the handicapped are now available in the Southwest Region:

1. State law requires the State to plan, develop, and implement a comprehensive system of services and facilities for the handicapped (A.S. 47.80.100). Therefore, the State is obligated to assist the Southwest Region to design and implement appropriate services.

2. The Bristol Bay Area Health Corporation and Bristol Bay Native Association which provide services throughout the region, are in a position to lead the way in planning and delivery of services for the handicapped. These organizations should consider contracting with the State to provide in-home services and other support services throughout the region.

3. The region has a chance to build on local values. People express strong values of self-reliance, respect for elders, concern for child development, and desire to look after one's own family members and neighbors. Many communities have at least some positive examples of mutual aid to families with disabled members. These values may present a real challenge to the acceptability of formally organized home support services, but they also provide a strong foundation for support services dedicated to empowerment.

4. Consumer organization and participation are essential. Alaska's legislature has proven responsive to direct expressions of citizen concern for people with handicaps. In particular, parents of people with disabilities and disabled people themselves are willing to assist. If service users organize their concern for home and family support and if service providers can develop meaningful strategies for working together to develop more powerful support services, it might be possible to influence State policy and appropriations.

5. The Bristol Bay Area Health Corporation and Native Association and local communities can explore the possibility of developing a new role for home and family support specialists. Community health aides have established themselves as a vital service, but their priority is, necessarily, on acute care and care for children. It would take some time for home and family support services to become established in each community, but long term care is becoming more important as communities grow. Developing new competencies for people in small villages would be a further step toward building local skills and career options.

6. Organizations outside the region, such as Alaska Resources for the Moderately and Severely Impaired, (ARMSI) and community service organizations have people with skills and experience who can be resource people to in-region groups as they develop homemaker, home health, and other local support services.

CHAPTER 11

THE SOUTHEAST REGION

Demographics

The Setting

Southeast Alaska consists of a 550-mile strip of coastal land and numerous islands, stretching from the Malaspina Glacier south of Icy Bay to the Portland and Pearse Canals north of Prince Rupert, British Columbia. On the north, south, and east, the region is bordered by Canada; the Gulf of Alaska lies on the west. The total land area of 42,000 square miles is greater than the combined areas of New Hampshire, Vermont, Massachusetts, New Jersey, Delaware, and Rhode Island.

All of the communities of Southeast Alaska are on islands or on the coast, and the vast majority are separated from each other by water, mountainous terrain, or glaciers. With few exceptions, the only way to travel between communities is by boat or plane, as there are no roads except for short, local streets. The Alaska Marine Highway System operates through the Inside Passage from Skagway to Seattle. The Haines Highway offers the only means of land access, running from the ferry terminal at Haines to the Alaska Highway at Haines Junction, Yukon Territory.

The Southeast Region has been divided into subregions for purposes of planning and service delivery. The subregions, which are based upon census divisions, are consistent with transportation and economic patterns. With the exception of the Native population, which relates to the Mount Edgecumbe Hospital in Sitka for certain kinds of care, the subregions also reflect health service delivery patterns. (Southeast Alaska Health Systems Agency) The four subregions are:

1. The Ketchikan subregion -- consisting of the Prince of Wales, Ketchikan, and Outer Ketchikan census divisions, which encompass Prince of Wales, Annette, and Revillagigedo Islands, the mainland from the Bradfield Canal to the Portland and Pearse Canals, and numerous small islands.

2. The Wrangell/Petersburg subregion -- composed of the Wrangell/Petersburg census area, which includes the mainland and islands from the Bradhill Canal to Frederick Sound.

3. The Sitka subregion -- consisting of Baranof Island north of Whale Bay.

4. The Juneau subregion -- composed of the Skagway-Yakutat-Angoon, Haines Borough, and Juneau Borough census divisions and including northern Chichagof and Admiralty Islands and the mainland from Frederick Sound to the Malaspina Glacier.

Southeast Alaska is coterminal with the Sealaska Native Regional Corporation and includes the Ketchikan Gateway, Sitka, Haines, and Juneau Boroughs.

The People

The total population of Southeast Alaska was 55,985 in 1981. Approximately 18% of the people were Native; 77.9% were white; and 4.1% were of other races. (Southeast Alaska Health Systems Agency) The larger communities, such as Juneau and Ketchikan, are overwhelming non-Native. Other villages, such as Angoon are over 88% Native. Most Natives in Southeast Alaska are either Tlingit or Haida Indians.

The population of the Southeast Region, although younger than the United States average, is older than the statewide population. Overall, 36.68% are under the age of 21; 4.74% are over 65. The senior citizen population ranges from a low of 3.95% of the population in the Juneau area and Prince of Wales-Outer Ketchikan census divisions to a high of 5.72% in the Wrangell/Petersburg subregion. (U.S. Department of Commerce, Bureau of the Census)

According to the 1980 census, 50.3% of the Southeast Region's population is male, as compared to 54% male in Alaska as a whole and 49% male nationwide. (U.S. Department of Commerce, Bureau of the Census)

Table 11-1 depicts the population of the Southeast Region by age and subregion. With an average annual growth from 1970 to 1981 of 2.87%, the region is expected to grow to 60,799 people by 1984 and 67,218 by 1988, as shown in Table 11-2. Appendix A contains population projections for 1984 and 1988 for the subregions of the Southeast Region.

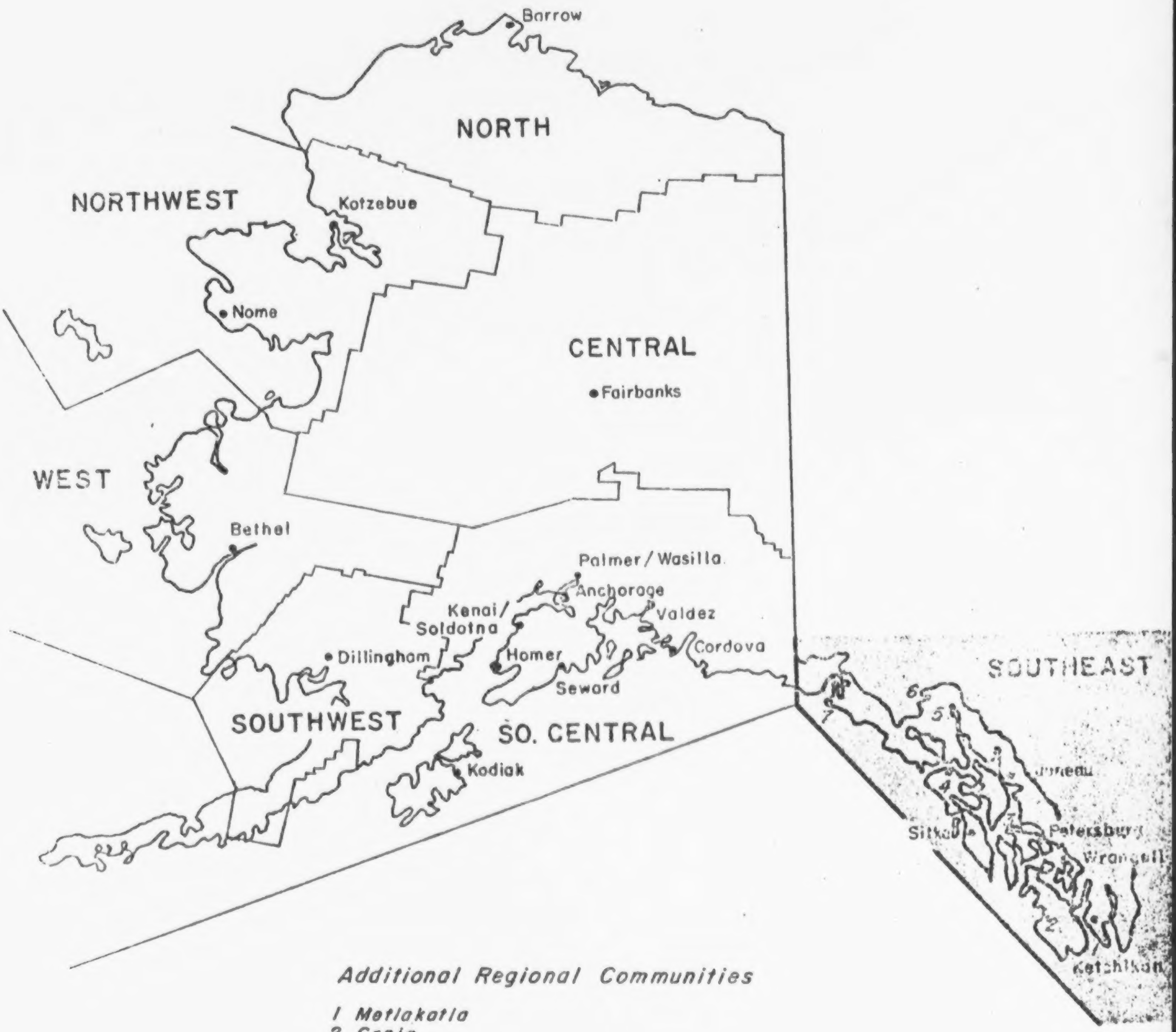
The Economy and Culture

Government is by far the largest employer in the Southeast Region, in part due to the location of the capital in Juneau. Federal, state, and local government employees accounted for 45.4% of all nonagricultural wage and salary workers in the region. Wholesale and retail trade was second, with 17% of the total employees.

Some growth took place in nonagricultural employment in the Southeast region between 1980 and 1982. Average employment increased at about 450 jobs (1.6%) per year. Taken as a whole, the region displayed a rather consistent albeit quiet employment picture. (Alaska Department of Labor, 1983c)

Construction, a typically seasonal industry, showed some interesting growth patterns in 1982, with specialty trade employment up 43% in January, 1983 compared to January, 1982. With the capital move issue resolved following the November election, building construction should increase in 1983. On the whole, Southeast construction employment slowly climbed in 1982. (Alaska Department of Labor, 1983c)

SOUTHEAST REGION


Barrow
NORTH
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Kotzebue
Nome
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Fairbanks
WEST
Bethel
Palmer / Wasilla
Anchorage
Kenai/
Soldotna
Valdez
Dillingham
Homer
Cordova
Seward
SOUTHWEST
SO. CENTRAL
Kodiak
SOUTHEAST
Juneau
Sitka
Petersburg
Wrangell
Ketchikan
1
2
3
4
5
6
7

Additional Regional Communities

1 *Metlakatla*
2 *Craig*
3 *Kake*
4 *Hoonah*
5 *Haines*
6 *Skagway*
7 *Yakutat*

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TABLE 11-1

POPULATION OF THE SOUTHEAST REGION, BY AGE AND SUBREGION, 1980

Area	Population by Age Group					
	0-2	3-5	6-20	21-64	65+	Total
Juneau subregion	1,368	1,218	6,176	14,883	1,041	24,686
Ketchikan subregion	886	755	4,038	8,666	793	15,138
Sitka subregion	498	421	2,096	4,427	361	7,803
Wrangell/Petersburg subregion	358	344	1,574	3,538	353	6,167
TOTAL	3,110	2,738	13,884	31,514	2,548	53,794

Source: U.S. Department of Commerce, Bureau of the Census. 1980 Census of Population, General Population Characteristics, Part 3 Alaska. PC80-1-B3 Alaska. Washington, D.C. August, 1982. Pp. 3-56 - 3-57.

TABLE 11-2

POPULATION OF THE SOUTHEAST REGION BY AGE GROUP, 1980 AND PROJECTED TO 1984 and 1988

Age Group	1980	1984	1988
0-2	3,110	3,514	3,885
3-5	2,738	3,095	3,421
6-20	13,884	15,692	17,349
21-64	31,514	35,616	39,376
65+	2,548	2,882	3,186
TOTAL	53,794	60,799	67,218*

* Total off slightly due to rounding.

Source: U.S. Department of Commerce, Bureau of the Census. 1980 Census of Population, General Population Characteristics, Part 3 Alaska. PC80-1-B3 Alaska. Washington, D.C. August, 1982. Pp. 3-56 - 3-57.

Average manufacturing employment saw a three-year decline from 1980 to 1982. A major factor behind this drop has been the fall in demand for lumber and pulp products. Logging employment fell 23% from June, 1981 to June, 1982, and saw mill employment dropped by 18%. Seafood processing employment also dropped due to the combined effects of the botulism scare and the lower runs of king crab and shrimp. (Alaska Department of Labor, 1983c)

Transportation, communications, and utilities employment has remained relatively stable since 1980. However, the late 1982 closure of the White Pass Railroad in Skagway contributed to a loss of 100 jobs over 1981. (Alaska Department of Labor, 1983c)

The unemployment rate in the Southeast Region was 14.8 in March, 1983, compared to a statewide rate of 12.1%. Subregions varied in unemployment rates from a low of 11.4% in Sitka, to a high of 24.5% in the Outer Ketchikan area. The Haines, Outer Ketchikan, and Prince of Wales census divisions all had unemployment rates above 21%, placing them among the highest in the state. (Alaska Department of Labor, 1983c)

Among the Native population, approximately half had incomes near or below the poverty level. Low incomes, plus the fact that the cost of living in isolated areas where many Natives live is higher than in urban areas, severely restricts the opportunities available to Native people.

Social Problems

The major social and health problems of the Southeast Region are similar to those of other areas. Alcohol abuse and accidents head the list, followed by mental health problems. Maternal and child health, including child abuse and neglect, family planning, problems of pregnancy, low-birth weight births, and congenital abnormalities, rank fourth. Other problems include non-alcoholic drug abuse, heart disease, dental disease, and nutrition. (Southeast Alaska Health Systems Agency)

The Target Population

As described in Chapter 5, all children who are substantially handicapped are considered to be developmentally disabled. These people make up about 3% of the age groups 0-2 and 3-5 and 1.87% aged 6-20. Adults are counted among the developmentally disabled only if their impairments arose in childhood. On the average, 1.49% of the population aged 21-64 and .5% aged 65+ are developmentally disabled. In addition, about 1.90% of the people aged 21-64 and 10% aged 65+ have other substantial limitations.

Table 11-3 summarizes the number of Southeast Region residents with substantial disabilities. Altogether, there were approximately 917 developmentally disabled and 854 otherwise disabled people in the Southeast Region in 1980. By 1988, those numbers are expected to rise to 1,160 and 1,079, respectively. Around 548 will be among the school-aged (3-20) population. Tables 11-3 to 11-7 estimate the numbers of substantially disabled people by age group for each subregion.

TABLE 11-3

ESTIMATED SOUTHEAST REGION POPULATION OF PERSONS WITH SUBSTANTIAL HANDICAPS, 1980

	Persons with Substantial Handicaps		
Age Group	Developmentally Disabled	Other	Total
0-2	93	0	93
3-5	82	0	82
6-20	259	0	259
21-64	470	599	1,069
65+	13	255	268
TOTAL	917	854	1,771

Sources: U.S. Department of Commerce, Bureau of the Census. 1980 Census of Population, General Population Characteristics, Part 3, Alaska. PC80-1-B3 Alaska. Washington, D.C. August, 1982. Pp. 3-56 - 3-57.

Governor's Council for the Handicapped and Gifted. 1981-83 Alaska Developmental Disabilities State Plan. Fairbanks, Alaska. August 1980. Pp. 25-29.

Urban Institute. Report of the Comprehensive Service Needs Study. DHEW-RSA. June, 1975. Pp. 57-58, 72.

Older Alaskans Commission. Phone interview with Lawry Robertson. January, 1983.

Methodology: See Appendix.

TABLE 11-4

ESTIMATED SUBSTANTIALLY DISABLED* POPULATION BY AGE, 1980 and PROJECTED TO 1984 and 1988

KETCHIKAN SUBREGION

	Substantially Disabled* Population		
Age Group	1980	1984	1988
0-2	26	28	29
3-5	23	24	25
6-20	75	79	83
21-64	294	309	321
65+	84	87	91
TOTAL	502	527	549

TABLE 11-5

WRANGELL/PETERSBURG SUBREGION

	Substantially Disabled* Population		
Age Group	1980	1984	1988
0-2	11	12	14
3-5	10	12	13
6-20	29	34	38
21-64	120	139	154
65+	37	43	47
TOTAL	207	240	266

* Includes both developmentally disabled and other disabled people.

Sources: U.S. Department of Commerce, Bureau of the Census. 1980 Census of Population, General Population Characteristics, Part 3, Alaska. PC80-1-B3 Alaska. Washington, D.C. August, 1982. Pp. 3-56 - 3-57.

Governor's Council for the Handicapped and Gifted. 1981-83 Alaska Developmental Disabilities State Plan. Fairbanks, Alaska. August, 1980. Pp. 25-29.

Urban Institute. Report of the Comprehensive Service Needs Study. DHEW-RSA. June, 1975. Pp. 57-58, 72.

Older Alaskans Commission. Phone interview with Lawry Robertson. January, 1983.

Methodology: See Appendix.

TABLE 11-6

ESTIMATED SUBSTANTIALLY DISABLED* POPULATION BY AGE, 1980 and PROJECTED TO 1984 and 1988

SITKA SUBREGION

	Substantially Disabled* Population		
Age Group	1980	1984	1988
0-2	15	16	18
3-5	13	14	15
6-20	39	43	48
21-64	150	166	182
65+	38	42	46
TOTAL	255	281	309

TABLE 11-7

JUNEAU SUBREGION

	Substantially Disabled* Population		
Age Group	1980	1984	1988
0-2	41	49	56
3-5	36	44	50
6-20	116	138	159
21-64	505	606	701
65+	109	130	149
TOTAL	807	967	1,115

* Includes both developmentally disabled and other disabled people.

Sources: U.S. Department of Commerce, Bureau of the Census. 1980 Census of Population, General Population Characteristics, Part 3, Alaska. PC80-1-B3 Alaska. Washington, D.C. August, 1982. Pp. 3-56 - 3-57.

Governor's Council for the Handicapped and Gifted. 1981-83 Alaska Developmental Disabilities State Plan. Fairbanks, Alaska. August, 1980. Pp. 25-29.

Urban Institute. Report of the Comprehensive Service Needs Study. DHEW-RSA. June, 1975. Pp. 57-58, 72.

Older Alaskans Commission. Phone interview with Lawry Robertson. January, 1983.

Methodology: See Appendix.

Community Descriptions

The Ketchikan Subregion

The Ketchikan subregion consists of Prince of Wales, Annette, Revillagigedo, and numerous small islands and mainland Alaska from the Portland and Pearse Canals to the Bradfield Canal. A secondary road links Ketchikan to the small settlements on the west coast of Revillagigedo Island; roads also join Craig and Klawock to the ferry terminal on Prince of Wales Island. Ferries put in at Metlakatla, Ketchikan, and Prince of Wales Island. Otherwise, all access to the subregion is by plane or small boat.

The population of this subregion was 15,414 in 1981, of which 74.8% live in the Ketchikan Gateway Borough. The Ketchikan Gateway Borough was predominantly white, with Natives comprising only about 16% of the population. In the Prince of Wales and Outer Ketchikan areas, Natives made up about 46% of the total. In Hydaburg, Klawock, and Kasaan, Natives constitute the majority. Most of the Natives in this subregion are of Haida and Tsimshian ancestry. (Southeast Alaska Health Systems Plan)

The Prince of Wales - Outer Ketchikan census area has the youngest population in Southeast Alaska, with 41.2% under the age of 21 and 3.95% over 65. In the Ketchikan Gateway Borough, corresponding proportions are 36.37% and 5.67%. Table 11-8 shows the 1980 population of the Ketchikan subregion by community.

Ketchikan, a Level III community, is the subregional center. It also serves as the hub for the cluster encompassing the Ketchikan East and North Tongass Highway communities. Ketchikan is home base for the Ketchikan Gateway Borough School District; the Gateway Community Mental Center; Women in Safe Homes; Ketchikan Youth Services; Island View Manor; the Ketchikan General Hospital; the community Health Center, which provides itinerant services subregionally; the Southeast Alaska Health Systems Agency; the Alaska Area Native Health Service itinerant dental program, which provides itinerant services to Hydaburg, Klawock, and Craig.

Metlakatla and Craig, the Level III communities in the Ketchikan subregion, provide some services for their surrounding areas. Metlakatla is the center for the Annette Island School District, and Craig supports the Craig City Schools. Hydaburg, a Level I village, also operates its own schools.

Residents of the Ketchikan subregion seek services in Ketchikan for most of their needs. Native residents sometimes go to Sitka for inpatient care at the Mount Edgecumbe Hospital. Hyder residents to go Stewart, British Columbia. Some specialized services not available in Ketchikan, such as orthodontia, can be obtained in Prince Rupert, British Columbia. For more intensive diagnosis and treatment, people usually seek attention in Seattle.

TABLE 11-8

POPULATION OF THE KETCHIKAN SUBREGION, BY COMMUNITY, WITH COMMUNITY LEVELS, 1980

Community	Level	Population
Annette	I	139
Cape Pole	I	29
Clover Pass	I	451
Coffman Cove	I	193
Craig	II	527
Herring Cove	I	99
Hydaburg	I	298
Hyder	I	77
Kasaan	I	25
Ketchikan	III	7,198
Ketchikan East	A*	387
Klawock	I	318
Metlakatla	II	1,056
Meyers Chuck	I	50
Mountain Point	I	396
North Tongass Highway	A*	1,722
North Whale Pass	I	90
Pennock Island	I	90
Point Baker	I	90
Saxman	I	273
Saxman East	A*	411
Throne Bay	I	320
Unassigned	-	899
TOTAL	-	15,138

*A = Adjacent communities. The Ketchikan East and North Tongass Highway areas are adjacent to Ketchikan; Saxman East is adjacent to Saxman.

Source: Alaska Department of Labor. Alaska Population Overview 1981. Juneau, Alaska. 1982. Pp. 16-17.

The Wrangell/Petersburg Subregion

The Wrangell/Petersburg subregion includes Wrangell and Kupreanof Island, numerous smaller islands in the vicinity, and the mainland from the Bradfield Canal to Frederick Sound. The population of the subregion was 6,455 in 1981, of whom approximately 21% were Native. This area had the largest concentration of senior citizens in the state, with 5.72% of the population aged 65 and older. Just over 36.9% were under 21 years of age. Table 11-9 gives the 1980 population of the subregion by community.

The Wrangell/Petersburg subregion is unusual in that two Level III, one Level II, and one Level I communities, Kake, Petersburg, and Wrangell all operate their own schools.

In human services beyond those available within the subregion, residents travel to Juneau, Ketchikan, and Seattle. Native residents sometimes seek inpatient care at the Mount Edgecumbe Hospital in Sitka.

TABLE 11-9

POPULATION OF THE WRANGELL/PETERSBURG SUBREGION, BY COMMUNITY,
WITH COMMUNITY LEVELS, 1980

Community	Level	Population
Kake	II	555
Kupreanof	I	47
Petersburg	III	2,821
Wrangell	III	2,184
Unassigned	-	474
TOTAL	-	6,081

Source: Alaska Department of Labor. Alaska Population Overview 1981. Juneau, Alaska. 1982. Pp. 16-17.

The Sitka Subregion

The Sitka subregion is coterminous with the Sitka Borough, which consists of Baranof, Kristof, Catherine, and Moser Islands, Chichagof Island below the Tenakee Inlet, and numerous smaller islands in the immediate vicinity. The population of the subregion was approximately 8,013 in 1981, of whom about 26% were Native. Almost 38.65% of the population were aged 0-21; 4.63% were 65 or older. Table 11-10 depicts the 1980 population of the subregion by community.

The city of Sitka, a Level III community, is the subregional center and primary service location for the area. Sitka is the regional center for Native health services since it is the site of the Mount Edgecumbe Hospital, Sitka also has a Pioneers Home, making it a center for senior residential services. Local and subregional services are provided by the Baranof Mental Health Clinic; Sitkans Against Family Violence; the Sitka Council on Alcoholism and other Drug Abuse; WIC; the homemaker program; itinerant public health nurse and dental services; the Sitka Community Hospital; and, the Sitka Borough School District.

For human service beyond those available within the subregion, residents travel to Anchorage and Seattle.

TABLE 11-10

POPULATION OF THE SITKA SUBREGION, BY COMMUNITY,
WITH COMMUNITY LEVELS, 1980

Community	Level	Population
Port Alexander	I	86
Sitka*	III	7,803
TOTAL	–	7,889

* The population figures for Sitka include the entire Borough other than Port Alexander. Communities encompassed . nclude Port Armstrong, Big Port Walter, Goddard, Mount Edgecumbe, Baranof, Todd, Chatham, and Chichagof, in addition to Sitka proper. Port Alexander is sometimes reported with the Wrangell/Petersburg subregion.

Source: Alaska Department of Labor. Alaska Population Overview 1981. Juneau, Alaska. 1982. Pp. 16-17.

The Juneau Subregion

The Juneau subregion includes Admiralty Island, the northern half of Chichagof Island, and the mainland from Frederick Sound to the Malaspina Glacier. The population of the subregion was approximately 26,103 in 1981. Within the subregion, there is considerable variations in the population. The Haines and Juneau Boroughs are predominantly white (approximately 85%), whereas the Skagway-Yakutat-Angoon census area is 44% Native. Juneau had the highest concentration of people aged 21-64 in the region and the second highest in the state (61.38%). The Skagway-Yakutat-Angoon area had only 54.97% of its people in that age group. Finally, with the State capitol in Juneau, that Borough is primarily government service oriented. In the smaller communities, such as Angoon and Hoonah, fishermen make up the majority of the work force. Table 11-11 shows the 1980 population of the Juneau subregion by community.

Juneau, as a Level II community, is the subregion center and primary seat for itinerant services. It is also the headquarters for the Juneau Borough

Schools, the Sealaska Corporation, and the Southeast Alaska Regional Health Corporation, not to mention State government.

Haines, Hoonah, Skagway, and Yakutat, as Level II communities, are largely self-sufficient for outpatient kinds of services and offer some services for surrounding residents. Each operates its own school system, as well.

For specialized services not available within the region, residents look to Anchorage and Seattle.

TABLE 11-11

POPULATION OF THE JUNEAU SUBREGION, BY COMMUNITY, WITH COMMUNITY LEVELS, 1980

Community	Level	Population
Angoon	II	465
Elfin Cove	I	28
Gustavus	I	98
Haines	II	993
Haines Borough (excluding Haines city)	with Haines	687
Hoonah	II	680
Juneau	III	19,528
Klukwan	I	135
Pelican	I	180
Skagway	II	768
Tenakee Springs	I	138
Yakutat	I	449
Unassigned	-	537
TOTAL	-	24,686

Source: Alaska Department of Labor. Alaska Population Overview 1981. Juneau, Alaska. 1982. Pp. 16-17.

Service Flow Patterns

Anchorage and Seattle are both specialized service centers for residents of Southeast Alaska. The farther south one goes, the more likely the people are to look toward Seattle.

Service flow patterns within the region vary somewhat from place to place, but the usual pattern is from Level I toward Level III communities, with itinerant services based in Level III subregional centers. The major centers are Juneau, Ketchikan, and Sitka, with secondary centers in Wrangell and Petersburg.

Available Services

Health Services

Health care services in Southeast Alaska are provided by three separate delivery systems. The federal government serves Alaska Natives, Coast Guard personnel, and veterans through its own facilities and by contract arrangements with private practitioners and community hospitals. The State provides primary care and health promotion services to all communities in the region through public health nurses and sanitarians. Private practitioners serve all portions of the population through fees for service, contract arrangements with the Alaska Area Native Health Service, and State and federal grants.

The Southeast Alaska Regional Health Corporation (SEARHC), through its Family and Social Health Program, provides ten communities with community health representatives. These people work primarily in the areas of social and mental health and help identify alternatives activities so that communities and individuals can achieve a higher level of wellness.

State public health nurses throughout the region provide childbirth/parenting classes, family planning clinics, and other services aimed at promoting health.

Both federal and state programs offer nutrition services and education for various target populations. The WIC program is administered by SEARHC in Juneau, Angoon, Hoonah, Craig, and Klawock. The Alaska Area Native Health Service, through the nutritionist at Mount Edgecumbe, provides nutrition education outreach to Native communities, as the Cooperative Extension Service does for all communities.

Maternal and child health and family planning services are provided primarily by physicians, nurse practitioners, physician assistants, and State public health nurses.

Behavioral health services are provided by a variety of agencies, some of which serve outlying communities on an itinerant basis. Community mental health centers include the Gateway Community Mental Health Center, serving the Wrangell/Petersburg and Ketchikan subareas; Baranof Mental Health Clinic, serving the Sitka subarea; and, the Juneau Mental Health Center, serving the Juneau subarea. Domestic violence programs are located in Juneau, Sitka, and Ketchikan. There are alcoholism programs in Juneau, Petersburg, Wrangell, Yakutat, Metlakatla, and Sitka, and in Angoon, Haines, Hydaburg, Kake, and Klukwan via the SEARHC program.

Ketchikan and its immediate vicinity has skilled nursing provided in the home provided by the Ketchikan public health center. This program also administers the home health aide program for the area. Similarly, the Juneau Health Centers offers some in-home nursing services.

Nurse practitioners and physician assistants provide primary diagnostic and treatment services in Ketchikan, Metlakatla, Craig, Mount Edgecumbe, Juneau, Pelican, Yakutat, Hoonah, Tenakee Springs, and Angoon.

State public health nursing services are based in Ketchikan, Craig, Wrangell, Petersburg, Sitka, Juneau, and Haines. Each of these programs provide itinerant services to neighboring villages and logging camps.

There are seven private and two Native Health Service dentists in Ketchikan. The Native Health Service dentist itinerate to Hydaburg, Klawock, and Craig. Metlakatla has a resident Native Health Service dentist. There is one private dentist in Wrangell and two in Petersburg, four in Sitka, twelve in Juneau, and one in Haines. In addition, there are three Native Health Service dentists in Sitka and two in Juneau. Itinerant services are provided to Kake, Angoon, Hoonah, Klukwan, Elfin Cove, Pelican, and Yakutat.

Ketchikan, Petersburg, Sitka, Juneau, and Haines each have one or more physical therapists. Ketchikan has eighteen physicians; Wrangell/Petersburg have four; Sitka has twelve; and Juneau has 27. Of the total of 61 physicians in the region, fourteen are employed by the Native Health Service, one is with the Coast Guard, and the rest are in private practice.

There were community hospitals in the five major communities. The Ketchikan hospital has 44 beds; Wrangell has nine; Petersburg has thirteen; Sitka has 24; and Bartlett Memorial in Juneau has 67. In addition, the Mount Edgecumbe Public Health Service Hospital in Sitka has 62. The region total is 199.

There are six long term care facilities in the Southeast Region, all offering both skilled and intermediate care. Island View Manor in Ketchikan has 48 beds. The Petersburg and Wrangell Long Term Care Facilities have twelve and fourteen beds respectively. Sitka Pioneers Home has 100 beds. Mount Edgecumbe operates an eight-bed long term care unit. Finally, St. Ann's Nursing Home in Juneau has 45 beds, bringing the regionwide total to 177.

Health services in the Southeast Region are summarized in Table 11-2. (Southeast Alaska Health Systems Agency)

Support Services

Support services are those which are needed in addition to adequate medical services, educational and vocational services, and employment opportunities in order for a substantially disabled person to live independently or with his/her family. There are three major types of support services--maintenance services, living skills training services, and material support services.

Maintenance services support or augment the family's efforts to care for a handicapped member living with them. In the case of a disabled adult living with a spouse or living independently in the community, maintenance services support or augment that individual's efforts at self-care and care of the home.

Living skills training services are formally-organized activities designed to foster the substantially handicapped person's skills for independent living and assimilation into the community. These services focus on developing the capabilities of the disabled person and augmenting the abilities of the family to assist their handicapped member to reach full potential.

Material support services provide or assist substantially handicapped individuals to obtain and maintain equipment, aides, and devices necessary for daily living or to meet special needs. General financial assistance and environmental and personal adaptive equipment are included.

Table 11-13 summarizes the support services available in the Southeast Region.

Maintenance Services

Southeast Alaska has a full range of day care services, ranging from informal "sitter" opportunities through licensed day care homes and centers. Some communities enjoy all of these options, while some have only informal means of child care.

The Alaska Department of Community and Regional Affairs operates the Day Care Assistance Program to help economically stressed families to offset the high cost of child care in some communities. This program supplemented child care payments for 1,273 children in eight communities in the Region during FY 1983. There were no substantially disabled children among this group, although the program is available to them if their parents meet the eligibility guidelines. The total budget for the Day Care Assistance Program in the Southeast Region was $1,067,122, with an average cost per child of $838.

In addition to generic day care services, 64 families in the Region are estimated to need respite care/specialized sitter services for their substantially handicapped members. There are three respite care service providers in the Region who served a total of 27 families in FY 1982 and who have a combined capacity of 23 families at a time. The average cost per hour for the three programs is $19.00, and budgets totalled $132,908 in FY 1983.

St. Jude's Center in Juneau offers both center- and apartment-based respite care with a capacity of five. St. Jude's served sixteen families in FY 1983 for a total of 4,524 hours. The average cost per hour of care was $19.43, and the total budget was $99,875. The program is licensed to serve developmentally disabled aged 0-18 and to provide emergency shelter to children aged 0-10.

TABLE 11-12

HEALTH SERVICES AVAILABLE IN THE SOUTHEAST REGION OF ALASKA, by COMMUNITY, 1983

		Prevention					Early Identification											
Community	Level	PC	SHE	PA	WCP	I	PNT	MDS	VHS	MTS	D&E	MS	DS	OT	PT	SSH	HHN	HHA
Ketchikan Subregion																		
Annette	I																	
Cape Pole	I																	
Clover Pass	I																	
Coffman Cove	I																	
Craig	II	L	L		L	L		L	L			L	I		I			
Herring Cove	I																	
Hydaburg	I	L			L	L												
Hyder	I																	
Kasaan	I																	
Ketchikan	III	L	L		L	L	L	L	L	L	L	L	L		L	L	L	L
Klawock	I																	
Metlakatla	II	L			L	L		L	L			L	L		I			
Meyers Chuck	I																	
Mountain Point	I																	
North Whale Pass	I																	
Pennock Island	I																	
Point Baker	I																	
Saxman	I																	
Thorne Bay	I																	
Wrangell/Petersburg Subregion																		
Kake	II	L			L	L							I		I			
Kupreanof	I																L	
Petersburg	III	L			L	L		L	L	L	L	L	L		L			
Wrangell	III	L			L	L		L	L	L	L	L	L		I			
Juneau Subregion																		
Angoon	II	L			L	L		L	L			L	I		I			
Elfin Cove	I												I					
Gustavus	I																	
Haines	II	L			L	L		L	L			L	L		L			
Hoonah	II	L			L	L		L	L			L	I		I			
Juneau	III	L			L	L	L	L	L	L	L	L	L		L	L	L	L
Klukwan	I												I					
Pelican	I	L			L	L		L	L			L	I					
Skagway	II	L			L	L									I			
Tenekee Springs	I	L			L	L		L	L			L						
Yakutat	II	L			L	L		L	L			L	I		I			
Sitka Subregion																		
Port Alexander	I																	
Sitka	III	L			L	L	L	L	L	L	L	L	L		L	L		

I = itinerant   L = locally-based

PC = Prenatal care
SHE = School health education
PA = Public awareness
WCP = Well-child program
I = Immunizations
PNT = Prenatal Testing

MDS = Medical/developmental screening
VHS = Vision and hearing screening
MTS = Metabolic screening
D&E = Diagnosis and evaluation of handicapping conditions
MS = Medical services

DS = Dental services
OT = Occupational therapy
PT = Physical therapy
SSH = Speech and hearing services
HHN = Home health nursing
HHA = Home health aide services

Sources: Southeast Alaska Health Systems Agency. 1982 Revised Health Systems Plan of the Southeast Alaska Health Systems Agency. Ketchikan, Alaska. February, 1982.

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TABLE 11-13

SUPPORT SERVICES AVAILABLE IN THE SOUTHEAST REGION, FY 1983

Type of Service	Availability*	Substantially Handicapped Clients Served	Average Cost Per Client	Total Costs for Handicapped Clients
MAINTENANCE SERVICES				
Day Care/sitter	A	NR	NR	NR
Day Care Assistance Program	P	0	$838	0
Respite/specialized sitter	P	27	$19.00/hour	$132,908
Homemaker	P	98	$1,043	$102,214
Home health aide	P	NR	$1,091	NR
Home health nursing	P	19	$1,180	$22,420
Personal aides and attendants	U	--	--	--
Transportation	S/I	NR	NR	NR
Recreation	S/I	NR	NR	NR
LIVING SKILLS TRAINING SERVICES	S/I	NR	NR	NR
MATERIAL SUPPORT				
Financial Assistance	A	NR	NR	NR
Environmental adaptive equipment	P	NR	NR	NR
Personal adaptive equipment	P	NR	NR	NR

* A = available; P = available in only some parts of the region; U = unavailable; I = informal; S = only through the school.

Sources: Alaska Department of Community and Regional Affairs, Division of Employment Opportunity. Day Care Assistance Programs Mid Year Summary. FY 1983. Juneau, Alaska. February, 1983.

Alaska Department of Community and Regional Affairs, Division of Employment Opportunity. Unpublished data concerning the day care assistance grant program, FY 1983. Juneau, Alaska. March, 1983.

Alaska Department of Health and Social Services, Division of Family and Youth Services. Computer print-out on homemaker services program utilization data. Juneau, Alaska. December, 1982.

Alaska Department of Health and Social Services, Division of Public Health, Section of Nursing. Home Health Aide Services, FY 1983. May 17, 1983.

Alaska Management Technologies. Correspondence with the Governor's Council for the Handicapped and Gifted. Juneau, Alaska. January, 1983.

Bergerson, Lois. Home Health Case Load. Correspondence with Dorothy Truran of the Governor's Council for the Handicapped and Gifted. Juneau, Alaska. May 17, 1983.

CHILD, Inc. Proposal to Provide Respite and Group Home Assistance for Developmentally Disabled Children. Submitted to the Alaska Division of Mental Health and Developmental Disabilities. Juneau, Alaska. July, 1982.

Gateway Opportunity Center. FY 82-83 Program Proposal. Submitted to the Alaska Division of Mental Health and Developmental Disabilities. Ketchikan, Alaska. 1982.

Governor's Council for the Handicapped and Gifted. Respite Care Providers Survey. Fairbanks, Alaska. December, 1982.

Ketchikan Association of Parents for People with Special Needs. KAPPS Respite Care Program. Ketchikan, Alaska. January, 1983.

St. Jude Center, Inc. Respite Program Proposal, 1982-83. Submitted to the Alaska Division of Mental Health and Developmental Disabilities. Juneau, Alaska. July, 1982.

Sitka Parent Association for Citizens with Special Needs. Sitka-PACS Respite Care Program Proposal for FY 1983. Submitted to the Alaska Division of Mental Health and Developmental Disabilities. Sitka, Alaska. July, 1982.

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The Ketchikan Association of Parents for People with Special Needs (KAPPS) respite care program has a capacity of ten clients. The services are provided in the clients' own homes in the communities of Ketchikan, Klawock, and Craig, with possible expansion planned for other areas of Prince of Wales Island and Metlakatla. This program was initiated in October, 1982, so it operated only part of FY 1983. During this time, it served two clients for a total of 356 hours of care at an estimated cost per hour of $48.45. The total budget was $13,812 in FY 1983. Hourly costs are expected to decrease as the client load increases.

The Sitka Respite Care Program, sponsored by the Parents Association for Citizens with Special Needs, has a capacity of eight clients who can be served in their own homes or in providers' homes. During FY 1982, nine families received 1,661 hours of service at an average hourly cost of $11.57. The total budget in FY 1983 was $19,220.

Homemaker services provide household assistance, chore service, and/or non-medical personal assistance to enable a person and his/her family to live at home. The Alaska Division of Family and Youth Services (DFYS) contracts with Alaska Management Technologies to provide homemaker services statewide. In the Southeast Region, sixteen communities have homemaker services available. In FY 1982, 256 people received homemaker services; of this number, 98 were substantially handicapped. On the average, each client had 85.5 hours of care at a cost of $1,043. The total budget for homemaker services in Southeast Alaska was $266,736 in FY 1982; the portion spent on substantially disabled people was $102,214.

Home health aide support is a special resource made available to individuals who need health-related personal care in order to maintain an independent, community-based living arrangement. This service is appropriate for individuals who, because of illness, injury, infirmity, or impairment, are unable to carry out personal health care tasks necessary to meet their own physical and/or emotional needs. Home health aide services were provided to 91 clients in eight Southeastern communities in FY 1983 through the Alaska Division of Public Health. The cost per client was $1,091, for a total of $99,303. The proportion of clients who were substantially handicapped is unknown.

The Alaska Division of Public Health offers home health nursing and other skilled in-home services through the health departments in Juneau and Ketchikan. Services are provided free of charge to all persons who have physicians' orders for such care. During FY 1983, the Juneau program served 105 individuals, of whom ten were substantially disabled. The Ketchikan program served 115 people, of whom nine were substantially handicapped. The average cost per client in both programs was $1,180. In Juneau, the total budget was $123,872, with $11,800 spent for services for the handicapped. In Ketchikan, $10,620 out of a total budget of $135,669 went for care of the handicapped.

While there is some need for personal aide and attendant care in Southeast Alaska, such care is not currently available.

Transportation and recreation services are generally not available for the handicapped in Southeast Alaska except as adjuncts to larger programs and the school districts. The Juneau Association for Retarded Citizens provides some recreational activities, and the Special Olympics program is ongoing in many communities, often as part of the school districts' special education activities.

Developmental Services

Developmental services are provided by the school districts and as adjuncts to other programs. Other training of disabled people and family members occurs on an informal basis through public health nurses, community health aides, and other individuals.

Material Support Services

Cash assistance is available to eligible individuals and families in the Southeast Region on the same basis as elsewhere in the state. The major categories of special assistance to the handicapped are Aid to the Disabled and Aid to the Blind, through the Alaska Division of Public Assistance, and Supplemental Security Income (SSI) payments, in accordance with the federal Social Security Act.

Personal adaptive equipment is provided to disabled children through Alaska's Handicapped Children's Program. The State Division of Vocational Rehabilitation supplies personal and environmental equipment and home retro-fits for disabled adults in Ketchikan and Juneau who have vocational rehabilitation potential. For other people, particularly adults with little vocational potential and those outside of Juneau and Ketchikan, adaptive equipment is generally unavailable except through private or third-party payment or on an informal basis.

Residential Services

Services Available in the Southeast Region

Over 95% of the disabled people in every region live in their home communities in natural environments. For the other five percent, the Southeast Region offers a range of augmented, devised, and protective residential environments for its residents and for people from other parts of the state. Options range from foster care to long-term nursing care.

Augmented environments which were utilized in the Southeast Region in FY 1983 include foster care and subsidized adoptions, both administered by the Alaska Division of Family and Youth Services.

Subsidized adoptions enable adoptive placement of children who require medical services beyond the financial capabilities of their adoptive families. During FY 1983, there were three children in the Southeast Region who were subsidized adoptive placements. The average cost per child per day in subsidized adoptions was $9.86.

Foster care, as provided through the Division of Family and Youth Services, offers alternative home situations for nine substantially handicapped youngsters in the Southeast Region. Of these nine children, eight were residents of the Region prior to their placement in foster care; the other child was from the South Central Region. The average cost per client day in foster care was $14.28.

Devised environments provide services beyond those which are appropriate in augmented settings. There are four agencies offering devised residential services in the Southeast Region.

The CHILD Group Home in Juneau provides a devised environment for up to five developmentally disabled children. The program focuses on children who are mentally retarded but trainable and provides an environment conducive to development of independent living skills and potential employment in adulthood. A new program in FY 1983, the CHILD Group Home cared for three residents aged 6-20. The average daily cost per resident was $169.96 because of first-year start-up and partial occupancy. FY 84 average daily cost is $59.00.

The Gateway Opportunity Center Group Home in Ketchikan operates two group homes, each with a capacity of five adults. These facilities both have programs for three clients who need close supervision and two clients who are more independent. In FY 1983, six individuals lived in the group homes at an estimated average daily cost per resident of $41.00.

The Ketchikan Teen Home offers residential group home services to troubled youth and is not designed specifically for the substantially disabled. However, during FY 1983, one disabled person did receive care there at an average daily cost of $81.61.

The REACH Group Home in Juneau provides a devised residential environment for five adults. The facility was at capacity in FY 1983, with five residents. The average daily cost of care per resident was $58.56.

The only protective residential environments for substantially disabled people in the Southeast Region are those provided by nursing homes. Island View Nursing Home, a 48-bed skilled and intermediate care facility in Ketchikan, cared for four substantially disabled people in FY 1983 at an average daily cost of $145.95 per resident. St. Ann's Nursing Home, a 45-bed skilled and intermediate care facility in Juneau, had two substantially disabled residents in FY 1983 at an average daily cost of $124.00 each. Finally, the Wrangell Long-Term Care Facility, with fourteen skilled and intermediate care beds, had three substantially disabled residents at an average daily cost of $113.08.

Table 11-14 shows utilization experience of residential facilities/programs in the Southeast Region, by home region of the clients.

Facilities Utilized by Residents of the Southeast Region

During FY 1983, eleven residents of the Southeast Region received care in augmented environments. Two school-aged children participated in the Hope Cottages specialized foster care program in Anchorage; three other children were in subsidized adoptive placements within their home region. Four adults took part in the Hope Cottages Independent Living Program in Anchorage; one was in the Access Alaska Independent Living Program in Anchorage; and, one was in the Fairbanks Rehabilitation Association's apartment program.

During this same time period, fifteen other residents of the Southeast Region were in devised environments. This group included two school-aged children in the Hope Cottages Children's Group Home in Anchorage and three in the CHILD Group Home in Juneau. Three adults lived in the Gateway Opportunity Center Group Home in Ketchikan, while two were in the Hope Cottages Adult Group Homes in Anchorage. Finally, five adults lived in the REACH Group Home in Juneau.

As is the case in other regions of the state, the Southeast Region had more of its residents in protective environments than in any other residential settings. Sixteen adults and two school-aged children were in these placements. Half of the total were in the Harborview Developmental Center. Two were in the Hope Cottages ICF-MR in Anchorage; the other six were in nursing homes in the Southeast and South Central Regions.

Residential Service Needs of Southeast Region Residents

In the Southeast Region, as Table 11-16 shows, approximately 54 substantially handicapped individuals needed some form of residential assistance in 1983. Fifteen of these people received the care they needed in their home region; 23 remained without service. Unlike the other regions, the Southeast Region does not appear to have any substantially disabled people who are placed in residential situations beyond their degree of need. However, there is a significant unmet need at all levels of residential services.

Costs of Residential Services Provided in the Southeast Region

As is usually the case, residential services provided in augmented environments in the Southeast Region are the least costly form of residential care. In FY 1983, the State budgeted $46,909 for the care of substantially disabled children in DFYS foster care and $10,800 for those in subsidized adoptions, for a total of $57,709 for the twelve young people in these settings.

With the exception of the CHILD Group Home in Juneau, devised residential environments in the Region cost more per client day than augmented settings but less than protective programs. For FY 1983, the State allocated $304,247 for devised residential services. The average daily costs per handicapped resident ranged from $41.00 at the Gateway Opportunity Center Group Homes to $169.96 at the CHILD Group Home. It should be noted that CHILD's FY 1984 rate of $59.00 would be a more accurate cost figure comparable to other devised residential group home options.

The three protective environments in the Southeast Region received a total of $427,496 in FY 1983 to cover the costs of care for substantially disabled individuals. Each of these settings was a nursing home with negotiated Medicaid reimbursement rates. Their average daily costs per handicapped resident ranged from $113.08 at the Wrangell Long Term Care Facility to $145.95 at the Island View Nursing Home in Juneau.

TABLE 11-14

UTILIZATION OF SOUTHEAST REGION RESIDENTIAL FACILITIES, BY HOME REGION OF CLIENTS WITH SUBSTANTIAL HANDICAPS, FY 1983

		Number of Clients by Home Region								
Program by Type of Environment	Location	SE	SC	C	SW	W	NW	N	Out of State	Total
AUGMENTED										
DFYS Foster Care		8	1	0	0	0	0	0	0	9
DFYS Subsidized Adoption	SC Region	3	0	0	0	0	0	0	0	3
DEVISED										
CHILD Group Home	Juneau	3	0	0	0	0	0	0	0	3
Gateway Opportunity Center Group Home	Ketchikan	3	1	1	1	0	0	0	0	6
Ketchikan Teen Home	Ketchikan	1	0	0	0	0	0	0	0	1
REACH Group Home	Juneau	5	0	0	0	0	0	0	0	5
PROTECTIVE										
Island View Nursing Home	Ketchikan	3	0	0	0	0	0	0	0	3
St. Ann's Nursing Home	Juneau	1	1	0	0	0	0	0	0	2
Wrangell Long Term Care Facility		0	2	0	0	0	0	0	0	2
TOTAL		27	5	1	1	0	0	0	0	34

Source: Governor's Council for the Handicapped and Gifted. Surveys of Provider Agencies, January - June, 1983. Fairbanks, Alaska. July, 1983.

TABLE 11-15

RESIDENTIAL PLACEMENTS OF SOUTHEAST REGION RESIDENTS WITH SUBSTANTIAL HANDICAPS, FY 1983

Program - Type of Environment	Location	Number of Residents by Age Group					
		0-5	6-20	21-64	65+	Unknown	Total
AUGMENTED							
Access Alaska Independent Living Program	Anchorage	0	0	1	0	0	1
DFYS Subsidized Adoptions	SC Region	0	3	0	0	0	3
FRA Apartment Program	Fairbanks	0	0	1	0	0	1
Hope Cottages Foster Care Program	Anchorage	0	2	0	0	0	2
Hope Cottages Independent Living Program	Anchorage	0	0	4	0	0	4
DEVISED							
CHILD Group Home	Juneau	0	3	0	0	0	3
Gateway Opportunity Center Group Homes	Ketchikan	0	0	3	0	0	3
Hope Cottages Adult Group Homes	Anchorage	0	0	2	0	0	2
Hope Cottages Children's Group Homes	Anchorage	0	2	0	0	0	2
REACH Group Home	Juneau	0	0	5	0	0	5
PROTECTIVE							
Harborview Developmental Center	Valdez	0	0	0	0	9	9
Hope Cottages ICF-MR	Anchorage	0	2	0	0	0	2
Island View Nursing Home	Ketchikan	0	0	0	0	3	3
Nakoyia Health Care Center	Anchorage	0	0	2	0	0	2
St. Ann's Nursing Home	Juneau	0	0	1	0	0	1
Wesleyan Nursing Home	Seward	0	0	1	0	0	1
TOTAL		0	12	20	0	12	44

Source: Governor's Council for the Handicapped and Gifted. Survey of Provider Agencies, January - June, 1983. Fairbanks, Alaska. July, 1983.

TABLE 11-16

NUMBERS OF SUBSTANTIALLY HANDICAPPED PERSONS NEEDING AND RECEIVING RESIDENTIAL PLACEMENTS, SOUTHEAST REGION, 1983

	Number of People				
Placement by Age Group	Needing Service	Receiving Service in Home Region	Receiving Service Outside Home Region	Unserved	Unserved in Home Region
AUGMENTED ENVIRONMENT					
0-5	4	0	0	4	4
6-20	5	3	2	0	2
21+	13	0	6	7	13
All ages	22	3	8	11	19
DEVISED ENVIRONMENT					
0-5	3	0	0	3	3
6-20	4	3	2	0	1
21+	11	8	2	1	3
All ages	18	11	4	4	7
PROTECTIVE ENVIRONMENT					
0-5	2	0	0	2	2
6-20	3	0	2	1	3
21+	9	1	3	5	8
All ages	14	1	5	8	13
TOTAL	54	12	17	23	39

Source: Governor's Council for the Handicapped and Gifted, FY 81-82 DD State Plan. Fairbanks, Alaska. Chapter 6.
Surveys of provider agencies. January, 1983.
Analysis of special education and residential placement data. June, 1983.

TABLE 11-17

COSTS AND FUNDING SOURCES FOR RESIDENTIAL SERVICES PROVIDED IN THE SOUTHEAST REGION, FY 1983

Facility/Program	Funding Source	FY 1983 Budget for Services to Persons with Substantial Handicaps		Average Daily Cost Per Handicapped Resident
AUGMENTED				
DFYS Foster Care	State General Fund	$46,909		$14.28
DFYS Subsidized Adoptions	State General Fund	10,800		9.86
DEVISED				
CHILD Group Home	State General Fund	77,500		169.96*
Gateway Opportunity Center Group Homes	State General Fund	74,825		41.00
Ketchikan Teen Home	State General Fund	29,788		81.61
REACH Group Home	State General Fund State & Federal AD/SSI State Revenue Sharing	94,134 24,000 4,000	$122,134	58.56
PROTECTIVE				
Island View Nursing Home	Federal Title XIX State General Fund	106,576 106,577	$213,153	145.95
St. Ann's Nursing Home	Federal Title XIX State General Fund	45,260 42,260	$ 90,520	124.00
Wrangell Long Term Care Facility	Federal Title XIX State General Fund	62,911 62,912	$123,823	113.08
TOTAL	All Sources	$789,452		-----

* First-year partial occupancy cost. FY 1984 daily cost is $59.00.

Sources: Governor's Council for the Handicapped and Gifted. Survey of Provider Agencies, January - June, 1983. Fairbanks, Alaska. July, 1983.

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Educational Services

Infant Learning Programs

Four Infant Learning Programs serve the Southeastern Region. They are based in Juneau, Ketchikan, Petersburg, and Sitka and together screened 121 children under the age of three and enrolled 92 handicapped children in FY 1982.

St. Jude Center, a private non-profit corporation in Juneau, provides integrated day care, handicapped pre-school and respite care services as well as Infant Learning Program (ILP) services to Juneau and southeastern residents. St. Jude Center's ILP serves Juneau-Douglas, Haines, Skagway, Yakutat and Hoonah. All but Juneau-Douglas are served on an itinerant basis by the ILP teacher from Juneau. The ILP provides a means to assess developmental levels of high risk children, identify problem areas and provide families with services and resources brought to the home. The program acts as a liaison between the children, their families, and the agencies which will ultimately be involved in caring for and planning for these children. (St. Jude Center Infant Learning Grant Proposal, 1983.)

In addition to birth defects which occur at a rate of about 7%, social and environmental factors contribute to disabilities and developmental delays. Alcohol abuse, drug abuse, and lack of adequate medical facilities and attention are a few. Fetal alcohol syndrome alone is estimated by the University of Washington researchers to occur in five per 1,000 births. Specific defects can and do occur in babies born to alcoholic mothers.

JUNEAU ILP

	Enrolled Start of Year	Referrals	Enrolled During Year	Terminated	Enrolled End of Year
FY 1980	10	35	4	7	7
FY 1981	7	23	11	9	9
FY 1982	9	30	12	6	15

The Southeast Island School District assumed responsibility for home-based Infant Learning Program services in Ketchikan and the surrounding area in July 1982. Ketchikan Youth Services operated the program before that, starting in November, 1978. However, the same teacher has provided the services since 1978.

Since 1978 many children under age three have been assessed for handicapping conditions. The program proposal for 1984 reports the numbers as follows:

	Assessed	Enrolled
Prince of Wales Island	9	6
Annette Island	6	4
Revilla Island	55	37

> "Since the ILP has been in operation for more than four years, the program is well known not only by longevity but by a constantly growing network of people connections."

The Petersburg Children's Center, a non-profit organization, operates the local Infant Learning Program serving local infants and their families. The Center also operates a day care center. The Infant Learning Program employs a half-time teacher who serves between ten and fourteen children who have a variety of developmental delays and physical handicaps.

> "The parents of these children need to learn methods of promoting their child's development, stimulating their growth and activity, and finding ways to overcome their handicaps. Parents must often travel out of the community to get diagnosis and help. This type of travel is disruptive to the family and is necessarily less frequent than it should be. They usually receive a medical diagnosis and treatment, leaving the parents and others in the community no better off in facilitating the infant's progress. These children would benefit from a multidisciplinary evaluation done locally and an Infant Learning Program Teacher to translate evaluation results into practical, daily interventions parents can carry out."

The teacher works closely with local support service personnel such as physical therapist, school district special education staff, physicians, health nurses, and Children's Center staff. Referrals come from the following sources in order of frequency:

1. Public Health Nurse,
2. Children's (Day Care) Center,
3. Concerned Parents or Citizens,
4. Physician,
5. School District.

The Sitka Parent Association for Children with Special Needs (PACS) was started as a support organization for families of individuals with handicapping conditions. Like many of the other ILP Boards, its members are parents, educators, and other interested community members. Sitka PACS has operated the Infant Learning Program since its inception there in 1980. The area served includes greater Sitka and the Mt. Edgecumbe area. In FY 1981, 34 children were screened and 15 were enrolled. In FY 1982, 20 were referred and 13 enrolled. In the first eight months of FY 1983, 18 were referred and nine were added to the existing enrollment of 16. One full-time teacher/program director is employed by the Board to provide ILP services.

Sitka PACS also provides respite care services to developmentally disabled children and adults in the area, has sponsored an annual Special Education Parent Team for Equal Rights (SEPTER) workshops in Sitka since 1981, and helps organize the annual Handicap Awareness Week in Sitka in conjunction with the school district, other local groups and businesses.

SOUTHEAST REGION

INFANT LEARNING PROGRAM ENROLLMENT STATISTICS, FY 1982

			Disabled Children				ILP Utilization				Funding (in thousands)		
Community	Agency	Total Pop. 0-2 FY80	At Risk	DD	Screened Svd	Enrolled	T	MDE	Contact Hours	Number Home Visits	FY82	FY83	FY84
Juneau	St. Jude Center	1,368	68	41	36	23	7	15	768	290	45.2	47.8	64.4
Ketchikan	SE Island Schools	886	44	27	34	34	9	8	413	192	39.1	42.2	51.3
Petersburg	Petersburg Day Care	358	18	11	23	13	7	9	464	172	20.4	21.1	19.7
Sitka	Sitka PACS	498	25	15	28	22	14	9	428	251	36.9	49.4	52.7
TOTAL		3,110	155	94	121	92	37	41	2,073	905	141.6	160.5	188.1

DD = developmentally delayed; T = terminated; MDE = received multi-disciplinary evaluations

Sources: Division of Public Health, Infant Learning Program Year-End Report, FY82, Anchorage, Alaska. September, 1982.
Division of Public Health, FY84 budget allocations, Infant Learning Program Coordinator. Anchorage, Alaska. August, 1983.

Pre-School

Children with handicaps who are between the ages of 3 and 5 may attend a local district special education pre-school program or go to Head Start. Sometimes parent and professional concerns about the possibility of a handicap or learning difficulty are unable to be confirmed in young children. Parents have a variety of alternatives to obtain both formal and informal assistance in parenting and in stimulating the early development of their children. Private day care programs and pre-schools often play an important role in this regard.

Head Start Programs are available in Juneau, Angoon, Hoonah, Klawock, Metlakatla, Haines, Hydaburg, Kake, and Ketchikan. Together they served 272 children in May 1983 with 20% or 53 of these children certified as handicapped. Generally Head Start programs in larger communities serve only mildly impaired children because the school district will provide special education services for more severely handicapped children. Districts can and do contract with Head Starts to serve pre-school handicapped children. Head Starts in smaller communities are often the only local pre-school or day care program of any kind outside of private in-home day care or babysitting. These seven small programs in the Southeast served one deaf, one visually handicapped, one seriously emotionally disturbed, and one physically handicapped child in addition to 27 other speech/language impaired children.

The 14 local school systems in Southeastern served 254 pre-school children with handicaps:

Cordova	4	Pelican	1
Haines	6	Petersburg	3
Hoonah	4	Sitka	42
Hydaburg	3	Skagway	2
Juneau	172	Yakutat	2
Ketchikan	15		

No age group data was available from the three Regional Education Attendance Areas.

Of the 254 in LEAs, there were 4 mentally retarded, 2 emotionally disturbed, 2 orthopedically handicapped, 1 neurologically impaired, 1 hard of hearing, and 8 multi-handicapped children.

In the Southeastern Region 10 to 11% of the preschool population, children ages 3 through 5, are identified as having some type of impairment and are receiving special education or therapy services at Head Start or local school district programs. Of these, 7% or .007 of the total age group population have been identified as severely handicapped.

Special Education

Since Alaska statutes require provision of special education services to children with handicaps at age three and Public Law 94-142 requires districts to conduct Child Find activities, complete evaluations, and initiate services promptly, many special needs children are already in the public school systems at age 5 or 6. For the Southeastern Region, 250 children under age five are receiving special education services. In fact, children under age 6 comprise 12% of the total special education enrollment of 2,067 students.

The remaining 1,813 students are in the 1st through 12th grades. The tables accompanying this section detail school and special education enrollments for each of the LEAs, REAAs and BIA schools in the Southeastern Region.

Juneau's total enrollment (4,346) is nearly double that of Ketchikan (2,376), and Ketchikan's is 600 or one-third more than Sitka enrollment (1,768). These three districts share 68% of the total student enrollment in the region. Similarly, they serve 67% of the region's 2,067 special education students.

As in other regions a wide variety of special education programs and program settings are available in different districts. Related services such as physical, occupational, or speech therapy are provided by local specialists in the larger districts or by itinerant private specialists who charge a fee for service and contract with districts to provide services.

The Southeastern Regional Resource Center (SERRC) in Juneau has provided psychological and special education services through grants and contracts to all southeast school districts on an itinerant basis since its beginning in 1977. SERRC's Special Services Unit employs school psychologists, communicative disorders specialists, special education consultants, a physical therapist, and an occupational therapist to provide assistance to school districts.

The Resource Center Board is comprised of administrators from the 17 southeast school districts. Because of demand and the lack of resource centers in other regions, all SERRC services are available to other regions from Anchorage as well as Juneau. SERRC services are:

Psychological Services
Speech and Language Services
Administrator and School Board Training in Provision of Special Services
Grant Writing
Rural Student Vocational Program
Policy and Procedure Manual Writing or Review
Program Evaluation On-Site Research
Staff Development and In-Service Training
Psychological Assessment
Child Study Team Consultation
Curriculum Planning and Development
Gifted/Talented Plan and Program Development
Guidance and Counseling
Instructional Aide Training
Modeling Instructional Techniques
Parent Training
Pre-Audit Assistance
Program Planning and Development
Provision of Direct Instructional and Administrative Service

Mount Edgecumbe High School at Sitka is a residential school for native Alaskans operated by the United States Bureau of Indian Affairs. The school was one of the major sources for education when villages and regional centers did not have high schools. Since the Molly Hootch case which successfully argued the right of native Alaskans to have local educational opportunities, local schools for K-12 have been built and staffed. However many students seek alternatives such as school attendance in larger communities or at Mt. Edgecumbe in order to share educational experiences with a larger group and to have more technical and specialized classes. Of the total 245 high school students at Mt. Edgecumbe, 13 receive special education services, all because of speech or learning disabilities. Whether Mt. Edgecumbe High School will be transferred to the State of Alaska and operated by the state as part of BIA's phase-out of educational services in Alaska is yet to be determined.

Eighteen Southeast students are placed outside the region for educational services. Six are placed out of state, nine are in the Anchorage Multi-handicapped Program, two are at Alaska Psychiatric Institute and one is at McLaughlin Youth Center. All of those at the Multi-handicapped Program reside at one of the Hope Cottages foster homes, group homes, or ten-bed intermediate care facilities. Costs and other information on these programs can be found in the South Central Region chapter and in statewide summary data in Chapters 3 and 4.

TABLE 11-19

SOUTHEAST REGION 1982-83 SPECIAL EDUCATION ENROLLMENT INFORMATION

School District	Number of Schools	Total Enrollment	Number of Sp Ed Students	% of Total Enrollment	Exceptionality											
					MR	HH	D	SI	VH	SED	OI	OHI	SLD	DB	MH	Out of District
LEAs																
Craig	2	160	20	13				10		1			9			
Haines	4	387	101	26	2	1		33	1	2			62			
Hoonah	2	237	49	20	3	2		21		1		1	20		1	
Hydaburg	2	102	20	20				1			2		17			
Juneau	11	4,346	660	15	19	3		405	2	2	12	2	205		10	7
Kake	2	214	51	24				19		2			29		1	
Ketchikan	6	2,376	368	15	7	4		93	1	34		5	219	1	4	5
Klawock	3	133	31	23	1		1	7					22			
Pelican	1	52	13	25				7			1		5			
Petersburg	2	607	88	14	1			40			1		36	1	9	1
Sitka	7	1,768	352	19	14			78	1	7	2		250			3
Skagway	2	237	25	11	3			7			1		14			1
Wrangell	2	504	86	17	5			15			1		63		2	
Yakutat	2	175	32	18				9					22		1	1
REAAs																
Annette Island	2	343	54	16	2	1		29		1			21			
Chatham	6	222	51	23	7			14		2		1	27			
SE Island	16	420	53	13	1			17			4		29		2	
BIAs																
Mt. Edgecumbe		245	13	5				6					7			
TOTALS		12,528	2,067**	16	65	11	1	811	5	52	24	9	1,057	2	30	5

** = Does not include out-of-district

Sources: Alaska Department of Education. 1982-83 School Year, P.L. 94-142 Count. Juneau, Alaska. December, 1982.
Alaska Department of Education. 1982-83 School Year, P.L. 89-313 Count. Juneau, Alaska. October, 1982.
U.S. Department of the Interior, Bureau of Indian Affairs, Anchorage Office - Data Search. Anchorage, Alaska. May, 1983

TABLE 11-20

SOUTHEAST REGION
1982-83 SCHOOL YEAR OUT-OF-DISTRICT PLACEMENTS

	Level of Home Comm.				Age Range				Exceptionality						Total Placements
Program Placement	I	II	III	IV	3-5	6-12	13-15	16-21	MR	D	SED	OI	SLD	MH	
Juneau															
Out of State			3			1		2			3				
Anchorage Mental Health Program			3			1	1	1						3	7
API			1					1			1				
Ketchikan															
Out of State			2				2				1			1	
Anchorage Mental Health Program			2					2						2	5
McLaughlin			1					1					1		
Sitka															
Out of State			1				1		1						
Anchorage Mental Health Program			1				1							1	3
API			1					1			1				
Petersburg															
Anchorage Mental Health Program			1					1						1	3
Yakutat															
Anchorage Mental Health Program		1				1								1	1
Skagway															
Anchorage Mental Health Program		1			1				1						1
TOTALS	0	2	18	0	1	3	5	9	2	0	6	0	1	9	20

Source: Survey of DOE-Office for Exceptional Children personnel and DOE Contract Programs. May - June, 1983.

TABLE 11-21

1982-83 SCHOOL YEAR FUNDING FOR SPECIAL EDUCATION PUBLIC SCHOOLS SOUTHEAST REGION

	F83 Funding Sources					
	Foundation Funding					
School District	Reg. Ed. Allotment	Special Ed. Allotment	Total	P.L. 94-142 Funding	P.L. 89-313 Funding	Total Funding
LEAs						
Craig	51,274	83,351	134,625	3,451		138,076
Haines	448,596	390,536	839,132	17,428		856,560
Hoonah	162,923	142,632	305,555	8,455		314,010
Hydaburg	81,340	45,846	127,186	3,451		130,637
Juneau	2,056,462	2,886,600	4,943,062	113,883		5,056,945
Kake	229,009	183,384	412,393	8,800		421,193
Ketchikan	1,046,467	1,146,150	2,192,617	63,498		2,256,115
Klawak	155,451	137,538	292,989	5,349		298,338
Pelican	131,660	47,544	179,204	2,243		181,447
Petersburg	335,956	353,184	689,140	15,185		704,325
Sitka	1,032,684	1,059,552	2,092,236	60,737		2,152,973
Skagway	89,361	91,692	181,053	4,314		185,367
Wrangell	873,083	220,740	1,093,823	14,839		1,108,662
Yakutat	201,517	152,820	354,337	5,522		359,859
REAAs						
Annette Island	297,342	220,740	518,082		11,008	529,090
Chatham	376,580	183,384	559,964		15,939	575,903
SE Island	349,151	183,384	532,535		9,009	541,554
TOTAL	7,918,856	7,529,077	15,447,933	327,165	35,956	15,811,054

Sources: Alaska Department of Education, Division of Education Program Support, F83 P.L. 94-142 and P.L. 89-313 Distribution Calculations, unpublished data. January, 1983.

Alaska Department of Education, Division of Management, Law, and Finance. Public School Foundation Program Calculations. March 2, 1983.

TABLE 11-22

1982-83 SCHOOL YEAR FUNDING FOR SPECIAL EDUCATION PUBLIC SCHOOLS AND BIA SCHOOLS
SOUTHEAST REGION

Schools	FY83 Funding Sources Funding 3017 Funds	 3101 Funds	 Total	 P.L. 94-142 Funding	 P.L. 89-313 Funding	 Total Funding
BIA Schools						
Mt Edgecumbe	17,391	27,431	44,822	0	0	44,822
TOTAL BIA SCHOOLS	17,391	27,431	44,822			44,822
	Reg. Ed.	Special Ed.	Total			
Total LEAs	6,895,783	6,941,569	13,837,352	327,165		14,164,507
Total REAAs	1,023,073	587,508	1,610,581		35,956	1,646,547
TOTAL PUBLIC SCHOOLS	7,918,856	7,529,077	15,447,933	327,165	35,956	15,811,054
TOTAL PUBLIC AND BIA SCHOOLS	7,936,247	7,556,508	15,492,755	327,165	35,956	14,855,876

Sources: U.S. Department of the Interior, Bureau of Indian Affairs, Anchorage Office - Data Run. Anchorage, Alaska. June 1, 1983.

Vocational Services

"Vocational services" is the term applied to the activities which assist a person in preparing for, securing, and maintaining employment. Some of the services are appropriately geared to school-aged children; others are more appropriate for adults. People with substantial handicaps need the same basic set of career and employment-oriented services as does the general population. The focus and intensity of services provided to people with substantial handicaps may be a bit different from those provided to the general population, but the goal of using these services remains the same-employment.

Alaska Division of Vocational Rehabilitation

The Alaska Division of Vocational Rehabilitation (DVR) is the major vocational agency of State government. DVR is charged under P.L. 93-112 and A.S. 23.15.010 with providing a full range of vocational evaluation, counseling, training, job placement, and follow-along services. These services are available through an office in Juneau and a branch office in Ketchikan. The Juneau facility serves its immediate vicinity as well as Angoon, Haines, Hoonah, Skagway, and Yakutat. During FY 1982, these offices served 242 clients.

DVR also conducts pre-vocational evaluations for secondary students enrolled in the Juneau Borough School District.

REACH, Inc.

Residential Employment Alternatives in the Community for the Handicapped (REACH) provides 30-day vocational evaluations, pre-vocational training, on-the-job training at work sites, and a sheltered workshop with a capacity of twelve. The agency develops competitive employment opportunities and currently oversees three community work sites in Juneau. Vocational follow-along services, including work adjustment and follow-up counseling, are available for all clients. The total budget for REACH's vocational programs in FY 1983 was $81,550.

Gateway Opportunity Center

The Gateway Opportunity Center (GOC) in Ketchikan provides 30-day vocational evaluations, pre-vocational training, and vocational training, placement, and follow-along services. Vocational training is offered in wood shop, shoe repair, laundry service, sign shop finishing, and park garbage, all based on sheltered workshop contracts. The sheltered workshop and community employment programs have a capacity of 25 clients.

School Districts

The school districts in the Southeast Region provide career and vocational education, pre-vocational training, and vocational training as components of the regular school curriculum. The numbers of approved vocational courses offered by each district in the 1982-83 school year were: Annette Island-22;

Chatham-34; Craig City-48; Haines Borough-21; Hoonah City-21; Hydaburg City-32; Juneau Borough-91; Kake City-28; Ketchikan Gateway Borough-60; Klawock City-12; Pelican City-13; Petersburg City-35; Sitka Borough-38; Skagway-24; Southeast Island-25; Wrangell City-37; and, Yakutat-20. These services and courses are provided to all interested students and are not designed especially for the substantially handicapped.

Enabling Services

Case Management Services

Informally, case management functions are carried out by particular agencies currently providing services to a disabled person and his or her family. For families involved in the Parent/Infant Learning Program, for example, the Infant Learning Teacher is looked to for guidance, information, and advice by the families and other agencies. The teacher may also assist, with family approval, in making referrals, planning, and obtaining, other needed services. Community health aides are the local, resident village health professionals who also serve this function for many, also on an informal basis as an adjunct to health care responsibilities. Division of Family and Youth Services Social Workers and Public Health's nurses also assist in case management as part of their provision of protective or other family services or health services.

There is no formal case management "system" for people with disabilities, just as there is no such system for the general population or for other population sub-groups. For most services to be provided, however, there are requirements for individual case service planning, development of habilitation, rehabilitation, special education, or family service plans, which is the primary responsibility of the providing agency in consultation and coordination with other related service or health personnel.

Guardianship Services

Guardianship and conservatorship services for people who are disabled can only be provided for legally after following a process of filing a petition and having a hearing in Superior Court. Since guardianship, responsibility for the person and decisions for the person, and conservatorship, management of the person's finances, mean that some or all of the disabled or incapacitated person's legal rights are taken away, special legal proceedings must take place to make sure that rights are not taken away without due process and without basis.

The First Judicial District includes the Southeast Region. Superior Court Judge's are at Ketchikan, Juneau, Sitka and Wrangell, and petitions may be filed and heard there. State law provides that a visitor must be appointed to investigate the situation of the person for whom a guardian is sought, to see if guardianship is necessary to protect the individual, and to identify people who might serve as guardian. If the Court determines that guardianship is necessary and that there is no relative or friend to be guardian, the Court can assign the Public Guardian to handle the person's affairs.

Staff Training and Manpower Development Services

Each agency has responsibility to provide for staff training. P.L. 94-142 requires training of teachers and other special education personnel. Title VI-B funds are provided to the school district based on special education enrollment and are utilized for training as well as child find activities. The special education outreach program, ARMSI, provides training to local people on an itinerant basis. The Division of Family and Youth Services has a training center in Anchorage for social workers employed by the Division. The Division of Public Health provides health education and training and sets aside money for annual training of infant learning program teachers.

Information and Referral

In the Southeast Region information about services and referral to services takes place informally and formally. Because of the small number of people living in villages and the small circle of service providers and service users in larger communities, word gets around fast about new services, new workers, and about people's impressions and perceptions of service delivery. Each service provider has a portion of the over-all responsibility to explain services, answer questions, make referrals, and coordinate with other workers and people in the community. A great deal of coordination is required because of the use of itinerant services. This means that local people must plan and coordinate schedules, trips, flights, and meetings between people in the villages such as the health aides as well as with itinerant providers who may be coming from Anchorage, Seattle, or beyond. At this point in time there is no over-all coordination of health and social services information and referral.

Protection and Advocacy Services

Protective services are provided by the Division of Family and Youth Services. Legal services are available on a resident basis in Juneau and Ketchikan and on an itinerant basis to the villages by Alaska Legal Services Corporation. The state Ombudsman's Office in Juneau accepts and investigates complaints about state agencies and provides itinerant service to other southeastern communities.

The only agency providing specialized protection and advocacy services to remedy violations of rights or due process, and to seek redress through negotiation, administrative, and legal means, and to provide assistance to disabled individuals who cannot access services themselves, is Protection and Advocacy for the Developmentally Disabled (P.A.D.D.). An advocate in Juneau can receive inquiries and provide services to the Northern Region on an itinerant basis.

In the Southeastern Region, PADD served twenty people in the first nine months of FY 1983; seven in Juneau, ten in Ketchikan and the balance in other southeast communities. The majority of concern's related to special education. Other problem areas were guardianship, habilitation, employment, finances, day care, and abuse/exploitation.

Obstacles and Opportunities

Obstacles

Every region has characteristics of geography, economics, population size, attitudes, and values which can present challenges in human service delivery. Many of these obstacles are similar from area to area; others are unique to particular regions or villages. Almost every problem can be overcome through dedication and creativity on the part of community residents. The following obstacles to service delivery for the handicapped have been identified in the Southeast Region:

1. The physical environment poses awesome challenges to regionwide service systems. The wide dispersal of people, long distances, and difficult travel conditions make it important to develop support competencies at the local level.

2. The Southeast Health Corporation and health systems agency have r centralized plan for regional service development.

3. Lack of services in the past contributed to inappropriate placements of some clients and no services for others. There are now people in residential placements outside of their home communities who could be returned if adequate support services were available. Community services are needed, especially placements in augmented environments and support services.

4. Community residents have attitudes in some cases which work against the development of local, community placements for severely disabled people. Positive attitudes and awareness of what can be accomplished locally must precede community acceptance of normalization.

Opportunities

The planning process enables communities to change obstacles into opportunities. Concerned service providers, clients, family members, and other interested people can work together to solve problems and implement community change.

Several opportunities in the area of services for the handicapped are now available in the Southeast Region:

1. State law requires the State to plan, develop, and implement a comprehensive system of services and facilities for the handicapped (A.S. 47.80.100). Therefore, the State is obligated to assist the northern region to design and implement appropriate services. The Governor's Council can help sponsor service planning activities in the region and can help provide technical assistance for local groups.

2. The region has a chance to build on local values. People express strong values of self-reliance, respect for elders, concern for child development, and desire to look after one's own family members and

neighbors. Many communities have at least some positive examples of mutual aid to families with disabled members. These values may present a real challenge to the acceptability of formal home support services, but they also provide a strong foundation for support services dedicated to empowerment.

3. The lack of a centralized master plan for regional service development creates a favorable climate for innovation in home and family support. If service providers can accept responsibility for planning together, a strong, varied system might be built from the bottom up.

4. Rural communities can explore the possibility of developing a new role for home and family support specialists. Community health aides have established themselves as a vital service, but their priority is, necessarily, on acute care and care for children. It would take some time for home and family support services to become established in each community, but long term care is becoming more important as communities grow. Developing new competencies for people in small villages would be a further step toward building local skills and career options.

5. All support services workers would benefit from consultation and training to expand the image of what abilities people can develop. The most effective training would come from active participation in individual planning meetings and hands-on assistance from professionals who visit homes along with workers to implement new plans. The region and the various service providers should give particular attention to provision of effective consultation and training services to village workers.

6. The Day Care Assistance Program is already organized and available in several communities. Other communities should explore this program as an avenue for providing day care services for disabled children. St. Jude Center in Juneau has experience in specialized integrated day care and can provide consultation and training to other day care providers.

7. Specialized sitter/respite services are well established in Juneau, Sitka, and now Ketchikan for developmentally disabled people. Families and service providers involved in starting and managing these programs are working together for these and other support services.

8. Consumer-based groups have joined with providers to develop local service agencies. Sitka PACS, KAPPs in Ketchikan, and Juneau Association for Retarded Citizens can work within their local communities and regionwide to improve service options and to develop community support services dedicated to personal/family empowerment.

9. REACH and CHILD in Juneau, GOC (Gateway Opportunity Center) in Ketchikan are developing a range of community residential, independent living, and vocational options in the region.

10. Local school districts and Southeast Regional Resource Center have significant resources for training, manpower development, parent training, and local service development.

11. The size and cohesiveness of the region, with several major communities as sub-regional centers, provide a strong basis for a wide range of locally responsive services to develop and benefit from shared training and resources.

APPENDIX A

FEDERAL TRANSMITTAL

APPENDIX A

FEDERAL TRANSMITTAL

Basic State Grant Program

The Developmental Disabilities Basic State Grant Program is a federally assisted state program designed to assure "...that persons with developmentally disabled receive the care, treatment, and other services necessary to enable them to achieve their maximum potential through a system which coordinates, monitors, plans, and evaluates those services..." (P.L. 95-602, Section 101(b)(1).

The specific purposes of the Basic State Grant Program, as outlined in Section 101 (b) (2) of Public Law 95-602, are as follows:

(A) to assist in the provision of comprehensive services to persons with developmental disabilities, with priority to those persons whose needs cannot be covered or otherwise met under the Education for All Handicapped Children Act, the Rehabilitation Act of 1973, or other health, education, or welfare programs;

(B) to assist States in appropriate planning activities; and,

(C) to make grants to States and public and private non-profit agencies to establish model programs, to demonstrate innovative habilitation techniques, and to train professional and paraprofessional personnel with respect to providing services to persons with developmental disabilities..."

The program works closely with the State Protection and Advocacy Agency, "... to ensure the protection of the legal and human rights of persons with developmental disabilities." (Section 101 (b) (1).

State Planning Council on Developmental Disabilities

The Governor's Council for the Handicapped and Gifted is Alaska's Council on Developmental Disabilities. It is a planning body composed of from 18 to 23 members including persons with developmental disabilities; immediate relatives or guardians of persons with developmental disabilities; and representatives of the principal State agencies, higher education training facilities, local agencies, and non-governmental agencies and groups concerned with services to persons with developmental disabilities. At least 50% of the Council membership must consist of persons with developmental disabilities or parents or guardians of such persons. Of that 50%, one-third must be persons with developmental disabilities and another one-third must be immediate relatives or guardians of persons with mentally impairing developmental disabilities. At least one individual must be an immediate relative or guardian of an institutionalized person with a developmental disability.

Members are appointed by the Governor for three year terms. A.S. 47.80 provides for rotation of terms and geographic ally diverse representation. A.S. 47.80 enumerates the requirements for membership, the scope and responsibilities of the Council, and requires compliance with federal developmental disabilities legislation and regulations.

Council Members

A list of Council members follows on the next page.

The Council staff is administratively located in the Department of Health and Social Services. Positions are part of the state personnel system. The Council staff and office are located physically separate from the Department of Health and Social Services at the following address:

600 University Avenue, Suite C
Fairbanks, Alaska 99701

Phone: (907) 479-6507
(907) 479-6940

Dorothy J. Truran, the Health and Social Services Planner II, serves as the executive director for the Council, reports to the Executive Committee and is supervised by the Council Chairperson.

The Health and Social Services Planner I has primary responsibilities for research, analysis, data collection, and preparation of materials and drafting of plans. This position is vacant.

Joyce A. Outten, the Clerk-Typist III, provides office management and all clerical support for the Council and staff.

BILL SHEFFIELD, GOVERNOR

GOVERNOR'S COUNCIL FOR THE HANDICAPPED AND GIFTED

UNIVERSITY PLAZA OFFICES WEST • SUITE C • 600 UNIVERSITY AVENUE • FAIRBANKS, ALASKA 99701
PHONE (907) 479-6507

REVISED: 11/18/82

MEMBERSHIP LIST

Jane White, Chairperson
Caroline Wolf, Chairperson-Elect
LaVedi Lafferty, Secretary/Treasurer

NAME/PHONE NUMBER	ADDRESS	CATEGORY
Thelma Bean Phone: None	Box 109 Kake, Alaska 99830	Consumer
Barbara Block Phone: 248-2804 (W) 344-1688 (H)	Star Route A, Box 1738 K Anchorage, Alaska 99507	Gifted/Talented Consumer
Terry Coon Director, Sp. Ed. Phone: 747-8624 (W) 747-3697 (H)	Sitka City Schools P.O. Box 1467 Sitka, Alaska 99835	Local Special Education Administrator Public-at-Large Educator, Local Organization
Robert Gregovich DD Program Manager Phone: 465-3370 (W)	Division of MH&DD Pouch H-04 Juneau, Alaska 99811	State Mental Health & DD Agency Gifted/Talented Consumer
Debra Keller Phone: 789-3236 (h)	8760 #9 Trinity Juneau, Alaska 99801	Consumer Local Service Agency
LaVedi Lafferty Phone: 456-2245 (H)	P.O. Box 929 Fairbanks, Alaska 99707	Consumer Local Service Agency
Phoebe Lindsey Director Phone: 465-3038 (W)	Office of State Health Planning & Development Pouch H-01 Juneau, Alaska 99811	State Health Planning Agency
Vacancy, Diane Schmeling's position		Consumer

NAME/PHONE NUMBER	ADDRESS	CATEGORY
Bill Mulnix Director Phone: 465-2970 (W) 364-3174 (H)	Office for Exceptional Children Department of Education Pouch F Juneau, Alaska 99811	State Special Education Agency
John Nuttall Phone: 486-3131 486-5594	Box 2554 Kodiak, Alaska 99615	Consumer Local Service Agency NEA Alaska
Kathe Parker Assistant Chief of Rehabilitation Services Phone: 243-5600 (W)	Division of Vocational Rehabilitation Department of Education 4100 Spenard Road Anchorage, Alaska 99504	State Vocational Rehabilitation Agency
John Pugh Deputy Director Phone: 465-3030 (W) 586-1598 (H)	Department of H&SS Pouch H-05 Juneau, Alaska 99811	State Social Services Agency Gifted/Talented Consumer
Dave Spence, M.D. Chief, Section of Family Health Phone: 465-3100 (W)	Division of Public Health Pouch H-06B Juneau, Alaska 99811	State Public Health Agency Gifted/Talented Consumer Local/Statewide Service Agency
Margie Tachell Phone: 225-9535	433 Main Street Ketchikan, Alaska 99901	Consumer Local Service Agency
Lurisse Ulen Phone: 456-2712 (H)	1037 Pedro Fairbanks, Alaska 99701	Consumer Local Service Agency
Blanche Walters Phone: 443-2718 (H) 443-2226 (W)	P.O. Box 728 Nome, Alaska 99762	Local Governmental Agency Consumer Postsecondary Education Commission
Jane White Phone: 776-8438	Route 1, Box 1290 Kenai, Alaska 99611	Consumer Gifted/Talented Consumer
Caroline Wolf Phone: 852-5600 (W) 852-3350 (H)	North Slope H&SS Agency P.O. Box 69 Barrow, Alaska 99723	Special Education Teacher Local Governmental Agency

BILL SHEFFIELD, GOVERNOR

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ALASKA GOVERNOR'S COUNCIL FOR THE HANDICAPPED AND GIFTED
COMMITTEES AND MAJOR TASKS 1982-1983

EXECUTIVE COMMITTEE	MAJOR TASKS
Jane White, Chair	Council Administration and Training
Caroline Wolf, Chair-Elect	Council Budget
LaVedi Lafferty, Secy-Treas	Interdepartmental Program Budget Information
John Nuttall, At-Large	A.S. 47.80 Regulations/Amendments
John Pugh, At-Large	

LEGISLATIVE COMMITTEE	MAJOR TASKS
Dave Spence, Chair	Report to Legislature
Debra Keller	Follow Introduction/Action on Bills
LaVedi Lafferty	Follow Federal Legislation/Budget
John Nuttall	Testify on Education/H&SS budgets

EDUCATION COMMITTEE	MAJOR TASKS
John Nuttall, Chair	Public Education Foundation Study Input
Barbara Block	G/T Policies - Manual Submittal/Field Testing
Kathe Parker	Liaison with Vocational Ed./E.T. Task Force
Blanche Walters	Vocational Education issues analysis/org.
Bill Mulnix	Special Education regulations
Terry Coon	Early Childhood Education Program Development/Coordination

PUBLIC AWARENESS COMMITTEE	MAJOR TASKS
Caroline Wolf, Chair	Travelling Exhibits development/distribution
Barbara Block	Guardianship Information
Margie Tachell	Up-date/Reprint "Where to Turn"
Lurisse Ulen	Services Booklets
Debra Keller	Develop Respite Care Manual

MEMBERSHIP AND NOMINATING	MAJOR TASKS
Lurisse Ulen, Chair	Solicit prospective members
LaVedi Lafferty	Inform Governor's Office of membership status
	Prepare slate of officers for nomination at May meeting

PLANNING COMMITTEE	MAJOR TASKS
John Pugh, Chair	State Plan 1984-1987
Phoebe Lindsey	Interior Alaska Home Support Services Project
Bob Gregovich	Training & Technical Assistance, Proposal Review
LaVedi Lafferty	CH2M Hill Housing Study
Jane White	

Council Committees

The Council has six standing committees:

Executive
Education
Legislative
Membership and Nominating
Planning and Evaluation
Public Awareness

Most Council business is handled by committees which meet one day before each quarterly Council meeting. Committees may meet by telephone conference call or through the legislative teleconference system.

Council Work Plan

The Council develops an annual work plan and calendar which are used to target and guide activities throughout the year.

A copy of the Council's detailed FY84 Work Plan, with prior year work plans, is attached.

Administering Agency for the Developmental Disabilities Program

The Department of Health and Social Services, Division of Mental Health and Developmental Disabilities is the state administering agency for the state's program. The Department has delegated to the Health and Social Services Planner II of the Council, responsibility for administration of the state plan. The Division handles all fiscal management of Council and federal developmental disabilities funds.

Administering Agency Staff

Dr. Robert Gregovich, Program Manager, Section of Developmental Disabilities, Division of Mental Health, Pouch H-04, Juneau, Alaska, 99811, is the administering agency staff person assigned to the Developmental Disabilities Program. The fiscal, management, and clerical staff of the Division in Juneau provide support necessary for the fiscal and administrative management of the program. The Division's phone number is 907-465-3370.

Major Concerns During the Three-Year Plan Period

Major concerns during the three year plan period are reflected in the regional and summary chapters of the plan, particularly in the Obstacles and Opportunities sections and in the Introduction and Summary, Chapter One.

These issues are statutory reform in A.S. 47.80 and A.S. 14.30; promulgation of program standards and regulations; service development in the priority service areas; elimination of inappropriate institutionalization; increased funding for home-based and community-based services; capacity-building and improvements in quality in the generic system.

The Council's planning process involves consumers, providers, local and state agency officials, and the public at large through participation in committee meetings, opportunities to present concerns at every Council meeting, public notice of meetings, A-95 review process, and on-going data-collection, surveys, and consultations with agencies and groups plus sponsorship of local planning conferences called "Search" conferences.

Survey results, client data, correspondence, communications, project data and reports, allied agency plans and surveys, special reports are analyzed and utilized to identify issues, develop strategies, and select service priorities.

Priority Service Areas

The federal Developmental Disabilities Act requires each state to assess the service needs of all developmentally disabled citizens, with special emphasis on four service areas identified in the legislation as requiring special consideration. These four areas are:

A. Case Management: Services which will assist persons with developmental disabilities in gaining access to needed social, medical, educational and other services; includes follow-along services which ensure a continuing relationship, lifelong if necessary, between a provider and a person with developmental disabilities and the person's immediate relatives or guardians; includes coordination services which provide support, access to and coordination of other services, information on programs and services and monitoring of progress. (Section 102(8)(C)(i)(ii))

B. Child Development Services: Services which will assist in the prevention, identification, and alleviation of developmental disabilities in children, and includes early intervention, counseling and training of parents, early identification and diagnosis and evaluation. (Section 102(8)(D)(i)(ii)(iii)(iv))

C. Alternative Community Living Arrangement Services: Services which will assist persons with developmental disabilities in maintaining suitable residential arrangements in the community, including in-house services (such as personal aides and attendants and other domestic assistance and supportive services) family support services, foster care services, group living services, respite care, and staff training, placement, and maintenance services. (Section 102(8)(E))

D. Non-Vocational Social-Developmental Services: Services which will assist persons with developmental disabilities in performing daily living and work activities. (Section 102(8)(F))

Elements of these priority service areas and services in Alaska are fully described in Chapter Four, Overview of Services, and in each of the Regional Chapters, Chapters Five through Eleven. The state's framework for looking at and developing these service elements statewide is addressed in Chapter Three.

Alaska's Priority Service Areas

Alaska has selected the following service priority areas for special emphasis during the next three years:

Child Development Services

- Infant Learning Programs
- Vision and Hearing Screening
- Educational services to children with low-incidence handicaps
- Occupational, physical, and speech therapy
- Family Counseling and Training
- Prevention and Public Awareness of Disabilities

Alternative Community Living Arrangements

Support Services

- Maintenance - day care, respite, homemakers, aides
- Developmental - personal skills and independent living skills training
- Material Support - financial assistance, adaptive equipment

Residential Options

- Natural and Augmented Environments - family care, foster care, adoptions, semi-independent living programs
- Devised Environments - group homes, community residences for 5 or less

These priorities were selected by the Council based on activities and input over the last three years. Descriptive information is contained in Chapters Two through Twelve.

Alaska's Service Goals

Provide local opportunities for every child with a disability to begin to receive educational and developmental services at birth, and to look forward to life-long educational services and opportunities through adult learning, community schools, and post-secondary programs.

Change funding patterns to those which empower local entities and consumers to purchase services and to those which provide incentives for community-based services.

Plan and advocate for funding and development of family support and community living services so that all people with disabilities may eventually be served in their home communities or in their home region.

Increase the knowledge and skills of service providers, families, and the public to improve the availability, accessibility, flexibility, and range of services, particularly of generic services.

Encourage formation and utilization of regional and local planning and support groups for the design and delivery of services.

Foster the use of multiple approaches to development of home-based community services to reduce and eliminate inappropriate institutionalization.

Improve administrative systems for services through revision and strengthening of A.S. 47.80 and A.S. 14.30, improvements in program standards, program regulations, methods for allocating funds, awarding contracts or grants, evaluating services, and monitoring programs.

Advocate for full special education funding, special education funding formulas, and funding accountability for all special education and related services in the state.

Promote efforts to coordinate the development and delivery of the full range of vocational education, career education, vocational training, job placement, sheltered workshop, and day-time services for people with disabilities beginning in junior high school and continuing through adulthood.

Plan year objectives may be found in the attached Council FY84 Work Plan.

STATE ALASKA

FY ENDING 9-30-84

TABLE 5-2
SUMMARY OF PROPOSED DEVELOPMENTAL DISABILITIES EXPENDITURES

FEDERAL DD FISCAL YEAR ALLOTMENT $ 250,000 Anticipated

(DDSP 7.1)

A. ALLOCATIONS TO STATE AGENCIES BY SOURCE OF FUNDS

Designated State Agencies 1	Non-Federal Funds				Federal* Funds 6	Total (5+6) 7
	State 2	Local 3	Non-Profit 4	Total (2+3+4) 5		
Dept. of Health and	$ 83,333	$	$	$ 83,333	$ 250,000	$ 333,333
Social Services	$	$	$	$	$	$
	$	$	$	$	$	$
Total	$ 83,333	$	$	$ 83,333	$ 250,000	$ 333,333

B. ALLOCATIONS TO STATE AGENCIES BY PURPOSE

Designated State Agencies 1	Total federal* & non-federal 2	Planning		Administration 5	Priority service areas				
		Council 3	Other 4		Case Mgt. 6	Child devel. 7	Altern. living 8	Non-voc. 9	Other 10
Dept. of Health &Social	F $ 250,000	$87,500	$	$	$	$85,333	$ 77,167		$
	NF$ 83,333	$	$	$ 50,000	$	$	$ 33,383		$
Services, DMH&DD	F $	$	$	$	$	$	$	$	$
	NF$	$	$	$	$	$	$	$	$
	F $	$	$	$	$	$	$	$	$
	NF$	$	$	$	$	$	$	$	$
Subtotals	F $	$	$	$	$	$	$	$	$
	NF$	$	$	$	$	$	$	$	$
Total	$ 333,333	$ 87,500	$	$ 50,000	$	$85,333	$110,500	$	$

* Basic Formula Grant Funds under P.L. 95-602

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DESCRIPTION OF THE PLAN TO BE USED TO PROTECT THE RIGHTS OF EMPLOYEES AFFECTED BY STATE ACTIVITIES IN COMMUNITY LIVING ARRANGEMENTS.

The only state-operated residential program in the institutional setting is Harborview Developmental Center, an ICF-MR (Intermediate Care Facility for the Mentally Retarded) located in Valdez. All other community living services are provided by local private organizations and the state intends to have this administrative pattern continue for the foreseeable future. Even though there are a number of persons residing at Harborview Developmental Center for whom placement in a less-restrictive setting is being considered, the state has no intention of reducing the number of employees at Harborview in the foreseeable future. Currently, there are 140 employees at Harborview.

If the number of employees working at Harborview Developmental Center were reduced, the state sees a number of alternatives available which would protect employees rights and interests. Because of the need for experienced employees to provide residential care for the developmentally disabled/severely handicapped, layoff would be the last alternative considered. Depending on the circumstances of the reduction and upon approval from the Alaska State Legislature, the following are possible alternatives to protect employees' rights in the event of a staffing reduction:

1. attrition
2. retraining
3. reclassification
4. transfer with moving expenses

It should be noted that all employees of Harborview Developmental Center are working under the Alaska State Merit System and the rules and regulations of that system would apply to the reduction of the work force unless special consideration were given through legislative directive.

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Application Procedure for Subgrantees

The following procedure is used for all subgrantee proposals. There may be more than one "Request for Proposal" cycle in any one fiscal year.

1. The Council prepares specifications for proposal requests and necessary requests for administrative approval for solicitation of proposals and award of grants.
2. The Council submits the specifications in "draft" r.f.p. form to the Division of Mental Health and Developmental Disabilities for approval.
3. The Council mails the request for proposals to agencies and advertises in newspapers in accordance with state procedures.
4. If requested, the Council can convene a meeting of prospective respondents to explain specifications. Any clarifications made to one potential respondent must be made to all others in writing.
5. The Council receives proposals from responding agencies.
6. The Council convenes a review committee meeting and proposals are reviewed and rated according to criteria established and included in the r.f.p. and according to Council review process and state plan.
7. Council staff completes final proposal negotiations with selected agencies based upon review committee recommendations.
8. Council staff submits necessary paperwork and grant award information to the Division of Mental Health and Developmental Disabilities.
9. The Division prepares Departmental paperwork, formal notification, and obtains necessary approvals and signatures.
10. The Division sets up payment procedure, sends paperwork to recipient agencies with copies to the Council.
11. The grantees begin projects.

APPENDIX B

ASSURANCES

1. The state assures that each designated state agency will make such reports, in such form and containing such information, as the Secretary (of Health and Human Services) may from time to time reasonably require, and keep such records and afford such access thereto as the Secretary finds necessary to verify such reports. (Sec. 133(b)(1)(C))

2. The state assures that it will maintain such fiscal control and fund accounting procedures as may be necessary to assure the proper disbursement of and accounting for funds paid to the State under Part C of Public Law 95-602. (Sec. 133(b)(1)(D))

3. The state assures that it has established a method for the periodic evaluation of the Plan's effectiveness in meeting the objectives set forth in the Plan. (Sec. 133(b)(2)(D))

4. The state assures that funds paid to the state under Section 132 will be used to make a significant contribution toward strengthening services for persons with developmental disabilities in the various political subdivisions of the state. (Sec. 133(b)(3)(A))

5. The state assures that part of the funds (under Part C) will be made available to public or nonprofit private entities. (Sec. 133(b)(3)(B))

6. The state assures that funds paid to the state under Section 132 will be used to supplement and to increase the level of funds that would otherwise be made available for the purposes for which federal funds are provided and not to supplant such non-federal funds. (Sec. 133(b)(3)(C))

7. The state assures that there will be reasonable state financial participation in the cost of carrying out the State Plan. (Sec. 133(b)(3)(D))

8. The state assures that buildings used in connection with the delivery of services assisted under the Plan will meet standards adopted pursuant to the Architectural Barriers Act of 1968. (Sec. 133(b)(5)(A)(ii))

9. The state assures that services assisted under the Plan are provided in an individualized manner consistent with the requirements of Section 112 (relating to habilitation plan). (Sec. 133(b)(5)(B))

10. The state assures that the human rights of all persons with developmental disabilities who are receiving treatment, services, or habilitation under programs assisted under this title will be protected consistently with Section III (relating to the rights of persons with developmental disabilities). (Sec. 133(b)(5)(C))

11. The state assures that special financial and technical assistance shall be given to agencies or entities providing services for persons with

developmental disabilities who are residents of geographical areas designated as urban or rural poverty areas. (Sec. 133(b)(4)(D))

12. The state assures that it has undertaken affirmative steps to assure the participation in programs under this title of individuals generally representative of the population of the state, with particular attention to the participation of members of minority groups. (Sec. 133(b)(5)(D))

13. The state assures that it has made, or will make, an assessment of the adequacy of the skill levels of professionals and paraprofessionals serving persons with developmental disabilities in the state and the adequacy of the state programs and plans supporting training of such professionals and paraprofessionals in maintaining the high quality of services provided to persons with developmental disabilities in the state. (Sec. 133(b)(6)(A))

14. The state assures that there has been provision for the maximum utilization of available community resources, including volunteers. (Sec. 133(b)(7))A))

15. The state assures that the composition of the State Planning Council meets the requirements of Section 137. (Sec. 133(b)(1)(A))

APPENDIX C

ALASKA GOVERNOR'S COUNCIL FOR THE HANDICAPPED AND GIFTED

WORK PLAN

PRESENT AND FUTURE WORK PLANS
GOVERNOR'S COUNCIL FOR THE HANDICAPPED AND GIFTED

Committee	Activity	Result		Future Action		
		Done/ Not Done	Comment	Needed Y/N	Priority H-M-L	Comment Suggested Strategy
EXECUTIVE	1984					
	1. Review and analyze Alaska Statute 47.80 for possible amendments along with regulations.			1. Y	High	1. Small contract or agreement for legal/technical research; Separate legal & policy questions, recommend definitions i.e. handicapped, d.d.
	2. Finalize the FY84 operating budget and monitor expenditures.			2. Y	Med	
	3. Monitor the proposed F85 budget for approval during the DH&SS, DOE, and the Governor's budget process.			3. Y	High	3. Ask DOE to include some Council funding in their F85 budget.
	A. Take an active role in legislative info activities regarding the Council budget.					A. Prepare budget info. Assign member-work on Council funding.
	4. Assist with organizational work for joint presentation to the HESS Committees and to follow up on the Council service priorities.			4. Y	High	4. Support Legislative Committee.
	5. Conduct orientation for new members and training for the Council.			5. Y	High	5. Important because of many new members-Policies & State Plan. John - Legislative process.
	6. Coordinate Council activities with P.A.D.D. and other agencies.			6. Y	Med	
	7. Supervise and evaluate staff and oversee Council operations.			7. Y	Med	
	8. Monitor/Coordinate task force for community services and deinstitutionalization.			8. Y	High	
	9. Action as needed on architectural barriers funds with GCEH.			9. Y	Med	

Committee	Activity	Result		Future Action		
		Done/ Not Done	Comment	Needed Y/N	Priority H-M-L	Comment Suggested Strategy
EDUCATION	1984					
	1. Foundation Support Study			1. Y	High	1. Member on sub-committee. Information to group/contractor. Survey of Sp Ed directors, Terry Coon, liaison with Sp Ed directors.
	2. Gifted/Talented Field Test			2. Y	High	2. Barbara Block, Shirley Craft. Recommend use of Policy Conf. people.
	3. Vocational Education Task Force			3. Y	High	3. Kathe, Blanch, Terry to assist and encourage DOE.
	4. ARMSI - Low Incidence Service's implementation.			4. Y	Med	4. August 19th Advisory meeting. Kathe sit in for John. During year, John or other consumer as Council representative.
	5. State Program for the Deaf - Housing planning			5. Y	Med	5. Check DOE F85 budget. Request meeting reports. Participate in developing survey questionaire. Participate on Deaf Education Committee & any residential services planning.

Committee	Activity	Result		Future Action		
		Done/ Not Done	Comment	Needed Y/N	Priority H-M-L	Comment Suggested Strategy
LEGISLATIVE	1984					
	1. HB 194.			1. Y	High	1. Work on needed changes with Reps and other groups.
	2. Foundation Study			2. Y	High	2. Council input. Gather information. Testify. Representation on any Special Ed. sub-committee.
	3. Priorities listed in the 1983 Legislative Priority Report.			3. Y	High	3. Support Legislative Committee. Review information. Testify. Re-use same report with up-dated pages and add new cover.
	4. Encourage, as parts of bills or requirements for funding capitol projects, incentives for private sector construction companies to use more barrier-free designs in their buildings.			4. Y	High	
	5. Testify on bills relating to handicapped and gifted.			5. Y	High	

Committee	Activity	Result		Future Action		
		Done/ Not Done	Comment	Needed Y/N	Priority H-M-L	Comment Suggested Strategy
MEMBERSHIP AND NOMINATING	1984					
	1. Gather resumes, review for completeness and forward to the Governor.					
	2. Prepare slate of nominees for Council officers.					

Committee	Activity	Result		Future Action		
		Done/ Not Done	Comment	Needed Y/N	Priority H-M-L	Comment Suggested Strategy
PUBLIC AWARENESS	1984					
	1. Decade for Persons with Disabilities.		Council approved idea of long-term effort and request for	1. Y	High	1. Meet with Governor and present ideas and needs.
	2. Promote incentives for private architects and construction of barrier-free buildings.		$2,500/year funds	2. Y	Low	2. Ask Governor to adopt initiative and urge private industry to do this. Ask Governor to do psas on this as part of Decade's ACCESS theme. Work with other organzations and local groups to help them push for local codes and ordinances and state-level action.
	3. Distribute public awareness materials, particularly the new license plate requirements. A. Print stickers on parking in handicapped space.			3. Y	High Short-Term	3. Run ads in Fairbanks, Anchorage, and Juneau papers to show the new form and say, for further information contact DVR.

Committee	Activity	Result		Future Action		
		Done/ Not Done	Comment	Needed Y/N	Priority H-M-L	Comment Suggested Strategy
PLANNING	**1984**					
	1. Work with the Executive Committee on the Task Force for development of a plan for community services & deinstitutionalization.			1. Y	High	1. Support and go-ahead from Governor and Commissioner. Meet with them in summer. Design work scope. Complete functional assessments of Harborview residents.
	2. Continue to follow up on the Interior Alaska Home Support Services Doyon Region with Search Conferences and further follow-up on what kinds of services will need to be developed in the Doyon Region.			2. Y	Med	2. Staff support to link consultants & experts to local sponsoring groups or committees. Possibles: Galena, Kenai, Anchorage, Ketchikan.
	3. If funds are available, provide training and technical assistance mini-grants to provider groups seeking to address state plan service priorities.			3. Y	Med	3. Use $7,500 designated for mini-grants. Staff to do RFP's for up to a specified amount, e.g. $1,500, committee review and select & award funds and suggest t.a. resources.
	4. Continue to work on the DD State Plan up-dates each year.			4. Y	High	4. Spend funds to print and orient people to plan.
	5. Continue to review and comment on state plans, regulations, and service proposals.			5. Y	M-Low	

APPENDIX D

ALASKA STATUTE 47.80

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ALASKA D. D. COUNCIL

LAWS OF ALASKA

1978

Source **Chapter No.**

SCS CSHB 472 AS 47.80 163

AN ACT

Relating to handicapped persons; and providing for an effective date.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF ALASKA:

* Section 1. INTENT. This Act is intended to assure the provision of quality services to those children and adults who have handicaps by reason of mental or physical disabilities, including persons qualifying for special education services under AS 14.30.180 - 14.30.350, other persons with the same or similar handicaps, and persons handicapped by mental retardation, cerebral palsy, epilepsy, autism or by other developmental disabilities defined in this Act. The primary objective of the Act is to bring together and make optimal use of all available resources -- federal, state, local, and private -- so that persons with handicaps may be served in the most effective and efficient way. A second goal of the Act is to assure the dignity of persons with handicaps, by reaffirming, and providing for the protection and advocacy of, their rights, which are the same rights as other people of the state of the same age and include the right to live as complete and normal lives as possible and develop their ability and potential to the fullest extent possible.

* Sec. 2. AS 47 is amended by adding a new chapter to read:

CHAPTER 80. PERSONS WITH HANDICAPS.

ARTICLE 1. RIGHTS.

Sec. 47.80.010. RIGHTS OF PERSONS WITH HANDICAPS. Persons with handicaps have the same legal rights and responsibilities guaranteed all other persons by the Constitution of the United States and federal laws and by the constitution and laws of the state. No otherwise qualified person by reason of having a handicap may be

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excluded from participation in, be denied the benefits of, or be subjected to discrimination under, any program or activity which receives public funds. Some persons with handicaps may be unable, due to the severity of their handicap, to exercise for themselves all of their rights in a meaningful way; for others modification of some or all of their rights is appropriate. The procedure used for modification of rights shall contain proper legal safeguards against every form of abuse, shall be based on an evaluation of the social capability of the person by qualified experts, and shall be subject to periodic reviews and to the right of appeal to higher authorities.

Sec. 47.80.020. PROTECTION AND ADVOCACY OF RIGHTS. The department shall establish a system to protect and advocate rights of persons with handicaps. The system

(1) has the authority to pursue legal, administrative, and other appropriate remedies to assure the protection of the rights of persons with handicaps; and

(2) shall be independent of any state agency which provides treatment, services or habilitation of persons with handicaps.

ARTICLE 2. GOVERNOR'S COUNCIL FOR THE HANDICAPPED AND GIFTED.

Sec. 47.80.030. GOVERNOR'S COUNCIL FOR THE HANDICAPPED AND GIFTED. There is established the Governor's Council for the Handicapped and Gifted. For budgetary purposes, the council is located within the Department of Health and Social Services but is the interdepartmental planning and coordinating agency of the Department of Health and Social Services, the Department of Education, and other departments which deliver services to persons who are handicapped or gifted. In addition, the council is the state planning council for purposes of federal laws relating to the handicapped or gifted.

Sec. 47.80.040. COMPOSITION. (a) The council consists of no fewer than 18 nor more than 23 members appointed by the governor in accordance with P.L. 91-517, P.L. 94-103, P.L. 94-142, as amended, and AS 14.30.231.

(b) No fewer than one-third of the members shall be representatives of the principal state agencies concerned with services for handicapped or gifted persons.

(c) No fewer than one-third of the members shall be developmentally disabled persons or parents or guardians of such persons, who are not officers or directors of an entity, or employees of a state agency, which receives funds or provides services under P.L. 91-517 or P.L. 94-103, as amended.

(d) The remaining members shall be appointed to represent the public at large, local agencies, nongovernmental agencies, and groups concerned with services to handicapped or gifted persons.

(e) Membership of the council shall at all times comply with the requirements of P.L. 91-517, as amended.

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(f) In the appointment of all members other than state agency members, due regard shall be given to geographically balanced representation of areas of the state and to representation of persons with a variety of different mental and physical handicaps.

Sec. 47.80.030. TERM OF OFFICE. (a) Council members' terms are three years. Of the initial appointees, one-third shall be appointed for one-year terms, one-third for two-year terms, and one-third for three-year terms.

(b) A vacancy occurring in the membership of the council shall be filled by appointment of the governor for the unexpired portion of the vacated term.

(c) Council members serve at the pleasure of the governor, notwithstanding their terms of office.

(d) It is the legislative intent that the governor replace any member who, by poor attendance or lack of contribution to the council's work, demonstrates ineffectiveness as a council member.

Sec. 47.80.060. COMPENSATION, PER DIEM, AND EXPENSES. Members of the council receive no salary but are entitled to per diem and reimbursement for travel and other expenses as authorized by law for boards.

Sec. 47.80.070. OFFICERS AND STAFF. (a) The council, by a majority of its membership, shall elect a chairman and other officers it considers necessary from among its membership, to serve on a yearly basis.

(b) The department shall provide for the assignment of personnel to the council to ensure that the council has the capacity to fulfill its responsibilities. The personnel shall be directly responsible to the council for performance of their duties.

Sec. 47.80.080. BYLAWS. The council, on approval of a majority of its membership, shall adopt and amend bylaws governing its composition, proceedings and other activities consistent with secs. 30 - 90 of this chapter and including, but not limited to, provisions concerning a quorum to transact council business and other aspects of procedure, frequency and location of meetings, and establishment, functions and membership of council committees.

Sec. 47.80.090. RESPONSIBILITIES. The council shall

(1) serve as a forum by which issues and benefits regarding current and potential services to handicapped and gifted persons may be discussed by consumer, public, private, professional, and lay interests;

(2) advocate the needs of handicapped and gifted persons before the executive and legislative branches of the state government and before the public;

(3) advise the executive and legislative branches of the state government and the private sector on programs and policies pertaining to current and potential services to handicapped or gifted persons and their families;

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(4) submit periodic reports to the commissioner of health and social services, the commissioner of education and to other appropriate departments, on the effects of current federal and state programs regarding services to handicapped or gifted persons; these reports shall include program performance reports to the governor, the federal government, and to state agencies as required by P.L. 91-517, P.L. 94-103, or P.L. 94-142, as amended;

(5) in conjunction with the Departments of Health and Social Services and Education, develop, prepare, adopt, periodically review, and revise as necessary an annual state plan prescribing programs which meet the needs of persons with developmental disabilities as required under P.L. 91-517 or P.L. 94-103, as amended;

(6) review and comment to commissioners of state departments on all state plans and proposed regulations relating to programs for persons with handicaps before the adoption of a plan or regulation; for this purpose, the appropriate departments shall submit the plans and proposed regulations to the council;

(7) recommend the priorities and specifications for the use of funds received by the state under P.L. 91-517, P.L. 94-103 and P.L. 94-142, as amended;

(8) submit annually to the commissioner of health and social services, the commissioner of education, and the commissioner of community and regional affairs a proposed interdepartmental program budget for services to handicapped or gifted persons which includes, insofar as possible, projected revenues and expenditures for programs implemented by state agencies, local governmental agencies, and private organizations; the interdepartmental program budget is an informational supplement to the regular annual budgetary submissions of the departments to the Office of the Governor;

(9) provide information and guidance for the development of appropriate special educational programs and services for exceptional children as defined in AS 14.30.-350;

(10) monitor and evaluate budgets or other implementation plans and programs for handicapped and gifted persons to assure nonduplication of services and encourage efficient and coordinated use of federal, state and private resources in the provision of services; members of the council, with the approval of the council, have access to information in the possession of state agencies subject to disclosure restrictions imposed by state or federal confidentiality or privacy laws; and

(11) perform other duties required under P.L. 91-517, P.L. 94-103, P.L. 94-142, as amended, or AS 14.30.-231, and as the governor may assign.

ARTICLE 3. PROGRAMS AND PLANS.

Sec. 47.80.100. PROGRAMS FOR PERSONS WITH HANDICAPS. (a) The Department of Health and Social Services, the Department of Education, and other departments of the state

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as appropriate, shall, in coordination, plan, develop, and implement a comprehensive system of services and facilities for persons with handicaps, which is consistent with the state plan adopted under sec. 90(5) of this chapter and is dispersed geographically within the state.

(b) The services required in (a) of this section are specialized services or special adaptations of services available to the general population and shall be directed toward the social, personal, physical, or economic habilitation or rehabilitation of persons with handicaps.

(c) Within the limits of appropriations and other available funds, the appropriate department may itself provide the services and establish, operate, and maintain the facilities required under (a) and (b) of this section, or it may provide the services or facilities entirely or in part through contractual arrangements with public or private agencies.

Sec. 47.80.110. PROGRAM PRINCIPLES. The system of services and facilities required under sec. 100 of this chapter shall accord with the principle that treatment, services, and habilitation shall be designed to maximize individual potential, minimize institutionalization, and shall be provided in the least restrictive setting, enabling a person to live as normally as possible within the limitations of the handicap.

Sec. 47.80.120. HABILITATION PLANS. A state agency, contractor, or grantee who is directly responsible for providing services to persons with handicaps shall develop an individual habilitation plan for each person whose program of services utilizes state funds. The plan shall be completed in writing and furnished to the department within 30 days of admission of a client to the program of services. The plan, its renewals, and any changes of it, shall have the written concurrence of the client, or his parent or guardian when appropriate, and the agency or contractor responsible for providing services. The development and content of a plan shall conform to requirements established by the department by regulation. Insofar as practicable, the requirements shall conform to those established for individual habilitation plans under P.L. 91-517 or P.L. 94-103, as amended. Each plan shall be time-limited, evaluated, and renewed at least annually.

Sec. 47.80.130. POWERS AND DUTIES OF THE DEPARTMENT.

(a) The department shall

(1) develop budgets and receive and distribute appropriations and funds under this section;

(2) adopt regulations regarding standards of services and facilities for persons with handicaps and the quality of services and the process by which services are to be delivered;

(3) adopt any other regulations necessary to implement this chapter;

(4) provide technical assistance to public and private agencies in planning, developing, and implementing

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programs to serve handicapped persons;

(5) operate programs and facilities, and enter into agreements, contracts, or grants necessary to provide services required under this chapter;

(6) take the actions and undertake the obligations which are necessary to participate in federal grant-in-aid programs and accept federal or other financial aid for the study, examination, care and treatment of the handicapped.

(b) For purposes of P.L. 91-517 and P.L. 94-103, as amended, the department is designated the sole administering agency; it shall make applications for, receive, and expend grants under P.L. 91-517 or P.L. 94-103, as amended, and otherwise exercise the powers and perform the duties and functions necessary to comply with P.L. 91-517 and P.L. 94-103, as amended.

(c) The Department of Education may make applications for, receive, and expend grants under P.L. 91-230 (The Education for the Handicapped Act), as amended, and otherwise exercise the powers and perform the functions necessary to comply with that Act.

Sec. 47.80.140. LICENSING AND CERTIFICATES OF NEED. (a) No person may establish or operate a residential facility without first obtaining a license to do so. The department by regulation shall provide for licensing of residential facilities which are not within the licensing provisions of AS 18.20.010 - 18.20.130, AS 47.35.010 - 47.35.080 or other law requiring state licensing of such facilities. Regulations of the department shall include but need not be limited to (1) standards of operation promoting and protecting public health, safety, and welfare, and (2) procedures governing applications for and issuance of licenses and duration, renewal, and revocation of licenses for cause. The department may at reasonable times inspect and examine residential facilities licensed under this subsection for conformity with licensing requirements.

(b) A certificate of need is required as a prerequisite for licensing a residential facility established after the effective date of this Act and not otherwise provided for in AS 18.07.031 - 18.07.111. A certificate shall be issued and regulated in the same manner as provided in AS 18.07.031 - 18.07.111 for certificates of need for health care facilities.

Sec. 47.80.150. LIABILITY FOR EXPENSE OF SERVICES. (a) A person with a handicap or his legal representative acting in a representative capacity, or his spouse or parents, shall pay or contribute to the payment of the charges for the care or treatment in the manner and proportion which the department finds is not detrimental to rehabilitation and which is within the responsible person's ability to pay. The charges may not exceed the actual cost of the care or treatment as determined by the department. The order of the department relating to the payment of charges shall be prospective in effect and shall relate only to charges to be incurred, except that if a person intentionally conceals his ability to pay, he shall be ordered

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to pay to the extent of his ability the charges accruing during the period of the concealment. The order of the department relating to the payment of charges by the person with a handicap or his legal representative, or his spouse or parents, shall be issued within six months of the date on which the charge was incurred. The department may make necessary investigations to determine the ability to pay. The order shall remain in full force and effect unless modified by subsequent court or department orders.

(b) As used in (a) of this section, the term "actual cost of the care and treatment" means either the rate provided for by a contract entered into under this chapter, or, in the absence of a contract, a daily rate fixed by the department, and includes expenses of transportation incidental to treatment and carrying out the intent of this chapter.

(c) A person with a handicap who receives benefits under this chapter who is developmentally disabled as defined in sec. 900(7) of this chapter or the person responsible for payment of charges for such a person, may not be required to pay more than $50 a month toward the charges for the care, treatment, and transportation in connection with treatment of the person with a handicap.

(d) The department may charge, or accept from a person money or property, for the care or treatment of an in-patient or out-patient or for other purposes, even if the payment is not required by an order of the department, so long as the total payments received do not exceed the actual cost of care or treatment.

(e) All money paid by the person with a handicap or on his behalf, under this section, shall be deposited in the state treasury.

(f) If an order of payment is entered by the department under this section and delinquency in the payment of any amount due the state under the order continues for a period of more than 30 days after the notification by the department to the legal representative, parent, or spouse of the person with a handicap, the state may proceed to collect the amounts due by appropriate proceedings. Actions to enforce the collection of payments may only be brought within three years after the date of notification of a delinquent payment.

Sec. 47.80.160. TRANSPORTATION. When an individual is to be treated under this chapter, the department shall arrange, upon the request of a person having a proper interest in the individual's treatment, and may pay for the individual's transportation to the designated facility, with appropriate medical or nursing attendants and by the available means which are appropriate and suitable. The department may pay return transportation of an individual and appropriate medical and nursing attendants. When practicable, one or more relatives or friends of the individual to be treated shall be permitted to accompany him. The department may pay necessary travel, housing and meal expenses incurred by one relative or friend in accompanying the individual to the facility if the department determines

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(1) that the best interests of the individual's health require that he be accompanied by the relative or friend;

(2) the relative or friend accompanying the individual is indigent.

Sec. 47.80.170. PROVISION FOR PERSONAL NEEDS UPON DISCHARGE. The department shall make arrangements which are necessary to ensure that

(1) no patient is discharged or placed on convalescent status from a designated facility without suitable clothing; and

(2) an indigent patient discharged or placed on convalescent status is furnished suitable transportation to his permanent residence in this state or other suitable place at the discretion of the department, and a reasonable amount of money to meet his immediate needs.

ARTICLE 4. GENERAL PROVISIONS.

Sec. 47.80.900. DEFINITIONS. In this chapter

(1) "council" means the Governor's Council for the Handicapped and Gifted created by sec. 30 of this chapter;

(2) "department" means the Department of Health and Social Services;

(3) "facilities for persons with handicaps" means publicly or privately operated facilities, or specified portions of facilities, designed primarily for the delivery of services to those persons; the term includes but is not limited to residential facilities;

(4) "habilitation" means education or training for the handicapped to enable them to function better in society;

(5) "least restrictive setting" means a residential or other setting for meeting the needs of a handicapped person which requires the least amount of restriction of personal liberty by enabling the person to function in as normal an environment as possible and to live as normally as possible, within the limitations of the handicap;

(6) "person with a handicap" means a person with a developmental disability as defined in (7) of this section or a person who is hard of hearing, deaf, speech impaired, visually handicapped, seriously emotionally disturbed, orthopedically or otherwise health impaired, or who has a specific learning disability; the term includes but is not limited to "exceptional children" as defined in AS 14.30.-350(1) and AS 47.20.050(1);

(7) "person with a developmental disability" means a person having a disability which

(A) is attributable to

(i) mental retardation, cerebral palsy, epilepsy, or autism;

(ii) any other condition found to be closely related to mental retardation because the condition results in impairment of general intellectual functioning or adaptive behavior similar to impairment resulting from mental retardation; or

(iii) dyslexia resulting from a disability described in (i) or (ii) of this subparagraph; and

(B) constitutes a substantial handicap to the person's ability to function normally in society;

(8) "residential facility" means a publicly or privately operated facility which provides 24-hour care for four or more persons with handicaps, excluding family, foster family, or adoptive homes;

(9) "substantial handicap" means a disability which prevents or substantially impedes the person's participating in and benefiting from the social, economic, educational, recreational, or other opportunities generally available to peers in the community who are not similarly handicapped.

* Sec. 3. AS 47.30.340(10) is amended to read:

(10) "mentally ill individual" means an individual having a psychosis or senile changes which substantially impair his mental health to the degree that he is a danger to himself or others; the definition does not include an individual suffering from acute alcoholism or drug addiction;

* Sec. 4. TRANSITION. The Governor's Council for the Handicapped and Gifted established under this Act succeeds to all contracts, rights, liabilities and obligations of the Alaska Developmental Disabilities Planning Council appointed under law repealed by this Act which are in effect on the effective date of this Act. The council also succeeds to all contract rights, liabilities, and obligations of the Special Education Advisory Council established under the authority of AS 14.30.231 and made part of the Governor's Council for the Handicapped and Gifted by Administrative Order No. 42A dated November 25, 1977. Records, equipment and other property of the former councils shall be transferred upon this Act's taking effect. The amount of any appropriation to the former councils which is encumbered but not expended on the effective date of this Act shall not lapse but shall be transferred to the Governor's Council for the Handicapped and Gifted concurrently with the effective date of this Act.

* Sec. 5. AS 18.05.031 is repealed.

* Sec. 6. This Act takes effect July 1, 1978.

Approved by the Governor: July 17, 1978
Actual Effective Date: July 1, 1978

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APPENDIX E

REFERENCES

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Alaska Crippled Children and Adults, Project TEACH (1983) ILP Grant Proposal for FY84. Fairbanks, Alaska. February.

Alaska Department of Community and Regional Affairs, Division of Employment Opportunity (1983a) Day Care Assistance Programs Mid Year Summary. FY 1983. Juneau, Alaska. February.

Alaska Department of Community and Regional Affairs, Division of Employment Opportunity (1983b) Unpublished data concerning the day care assistance grant program, FY 1983. Juneau, Alaska. March.

Alaska Department of Education, Division of Education Program Support (1983) FY 83 P.L. 94-142, and P.L. 89-313 Distribution Calculations, unpublished data. Juneau, Alaska. January.

Alaska Department of Education, Division of Management, Law, and Finance. (1983) Public School Foundation Program Calculations. Juneau, Alaska. March 2.

Alaska Department of Education, Division of Vocational Rehabilitation. 1982 State Facilities Plan. Juneau, Alaska.

Alaska Department of Education, Office for Exceptional Children (1983) Juneau, Alaska. March.

Alaska Department of Education (1983) School Districts Reports. Juneau, Alaska.

Alaska Department of Health and Social Services, Division of Family and Youth Services (1982) Computer print-out on homemaker services program utilization data. Juneau, Alaska. December.

Alaska Department of Health and Social Services, Division of Management and Budget (1982) A Study of Alaska's Adult Residential Care Facilities. Juneau, Alaska. August.

Alaska Department of Health and Social Services, Division of Management and Budget (1982) A Study of Alaska's Adult Residential Care Facilities. Juneau, Alaska. August.

Alaska Department of Health and Social Services, Division of Public Assistance (1983) Monthly Nursing Home Census and Per Diem Rates. Juneau, Alaska.

Alaska Department of Health and Social Services, Division of Public Health, Section of Nursing (1983) Home health aide services, FY 1983. Juneau, Alaska. May 17.

Alaska Department of Labor (1982a) Alaska Economic Trends. Juneau, Alaska. August.

Alaska Department of Labor (1982c) Alaska Population Overview 1981. Juneau, Alaska.

Alaska Department of Labor (1983a) Alaska Economic Trends. Juneau, Alaska. January.

Alaska Department of Labor (1983b) Alaska Economic Trends. Juneau, Alaska. February.

Alaska Department of Labor (1983c) Alaska Economic Trends. Juneau, Alaska. March.

Alaska Department of Labor (1983d) Alaska Economic Trends. Juneau, Alaska. May.

Alaska Department of Labor (1982b) Alaska Economic Trends. Juneau, Alaska. October.

Alaska Division of Public Health (1982) Infant Learning Program Year-End Report, FY82. Anchorage, Alaska. September.

Alaska Division of Public Health (1983) FY84 budget allocations, Infant Learning Program Coordinator. Anchorage, Alaska. August, 1983.

Alaska Division of State Health Planning and Development, Northern Alaska Health Resources Association, South Central Health Planning and Development, and Southeast Alaska Health Systems Agency (1982) The Data Appendix to State Health Plan 4. AK/DHSS/HP-82/24. Juneau, Alaska. April.

Alaska Division of Vocational Rehabilitation (1982) 1983 Budget Narrative. Juneau, Alaska. January.

Alaska Management Technologies (1983) Correspondence with the Governor's Council for the Handicapped and Gifted concerning homemaker services program utilization. Juneau, Alaska. January.

Aleutian-Pribilof Islands Association Health Corporation (1979) Tribal Specific Health Plan. Don Bantz and Associates. Anchorage, Alaska.

American Association on Mental Deficiency

Appel, Bob (1983) Personal communication to Laurie Goggin of the Governor's Council for the Handicapped and Gifted. Dillingham, Alaska. April.

Arctic Environmental Information and Data Center (1975a) Alaska Regional Profiles: Northwest Region. Volume V. Juneau, Alaska.

Arctic Environmental Information and Data Center (1975b) Alaska Regional Profiles: Yukon Region. Juneau, Alaska.

Bergerson, Lois (1983) Home Health Case Load correspondence with Dorothy Truran of the Governor's Council for the Handicapped and Gifted. Juneau, Alaska. May 17.

Bergerson, Lois (1982) Letter to Cheryl Thomas of the Institute of Social and Economic Research concerning functionally disabled persons. Juneau, Alaska. August.

Best-Sigford, Barbara, Robert H. Bruininks, K., Charlie Lakin, Bradley K. Hill, and Laird W. Heal (1982) Resident Release Patterns in a National Sample of Public Residential Facilities. *American Journal of Mental Deficiency*. Vol. 87, No. 2, Pp. 130-140.

Bethel Social Services, Inc. (1982) Developmental Disabilities Program Proposal for FY 1983. Submitted to the Alaska Division of Mental Health and Developmental Disabilities. Bethel, Alaska. July.

Boggs, Elizabeth M. and R. Lee Henney (n.d.) *A Numerical and Functional Description of the Developmental Disabilities Population. Developmental Disabilities Project of National Significance.* #54-P-71220/5-02.

Boggs, Elizabeth M. and R. Lee Henny. *A Numerical and Functional Definition of the Developmentally Disabled Population, 1979. 1976 Survey of Income and Education in the U.S., Census Bureau.* 1980 Census.

Bristol Bay Area Health Corporation (1982) 1982 Annual Report. Dillingham, Alaska.

Central Peninsula Mental Health Center (1982) FY 1983 Proposal for Continuing Respite Care Services. Submitted to the Alaska Division of Mental Health and Developmental Disabilities. Kenai, Alaska. July.

CHILD, Inc. (1982) Proposal to Provide Respite and Group Home Assistance for Developmentally Disabled Children. Submitted to the Alaska Division of Mental Health and Developmental Disabilities. Juneau, Alaska. July.

Child Abuse and Developmental Disabilities Essays, 1980.

Copper River Native Association Health Department (1979) Tribal Health Plan. Don Bantz and Associates. Anchorage, Alaska.

DD - The Orientation Notebook.

Dowler, Liz (1983) Conversation with Laurie Goggin of the Governor's Council for the Handicapped and Gifted concerning Alaska Vocational Services. Fairbanks, Alaska. June 16.

Employment and Training Center of Alaska (1982) FY 1982-1983 Continuation Proposal. Submitted to the Alaska Division of Mental Health and Developmental Disabilities. Anchorage, Alaska. July.

Fairbanks Rehabilitation Association (1982a) FY 83 DD Proposal. Submitted to the Alaska Division of Mental Health and Developmental Disabilities. Fairbanks, Alaska. May.

Fairbanks Rehabilitation Association (1982b) Summary of Activities, Fiscal Year 1982, July 1981 through June 1982. Fairbanks, Alaska. July.

Federal Register (1983) February 17, 1983. Pp. 7010-7011.

Gateway Opportunity Center (1982) FY 82-83 Program Proposal. Submitted to the Alaska Division of Mental Health and Developmental Disabilities. Ketchikan, Alaska.

Governor's Council for the Handicapped and Gifted (1978) Alaska Developmental Disabilities State Plan. Fairbanks, Alaska. January.

Governor's Council for the Handicapped and Gifted (1980) 1982-83 Alaska Developmental Disabilities State Plan. Fairbanks, Alaska. August.

Governor's Council for the Handicapped and Gifted (1982) Respite Care Providers Survey. Fairbanks, Alaska. December.

Governor's Council for the Handicapped and Gifted (1983a) 1983 Priorities for Gifted and Talented Students in Alaskan Schools for People with Disabilities and their Families. Fairbanks, Alaska.

Governor's Council for the Handicapped and Gifted (1983b) Survey of Provider Agencies, January - June, 1983. Fairbanks, Alaska. July.

Governor's Council for the Handicapped and Gifted (1983) Analysis of special education and residential placement data. June.

Heritage House (1981) Facility brochure and policies. Anchorage, Alaska.

Home Health Care, Inc. (1983) Phone conversation between Kay Burrows and Laurie Goggin of the Governor's Council for the Handicapped and Gifted concerning program utilization and budget. Anchorage, Alaska. July.

Hope Cottages (1982) Funding Proposal for FY 1983. Submitted to the Alaska Division of Mental Health and Developmental Disabilities. Anchorage, Alaska. July.

Independent Options Now (1982) Proposal for Funding, Fiscal Year 1983. Submitted to the Alaska Department of Education, Adult and Continuing Education. Anchorage, Alaska.

Ketchikan Association of Parents for People with Special Needs (1983) KAPPS Respite Care Program. Ketchikan, Alaska. January.

Kodiak Island Borough Health Resources Council (1975) An Assessment of Health Care Needs, Kodiak Island Borough. Anchorage, Alaska. October.

Kodiak Island Mental Health Center (1982) Residential Training Program Application for Contract. Submitted to the Alaska Division of Mental Health and Developmental Disabilities. Kodiak, Alaska. July.

Kodiak Island Native Association (1983) Annual Report 1982. Kodiak, Alaska.

Lakin, K. Charlie, Gordon C. Krantz, Robert H. Bruininks, Jane L. Clumpner, and Bradley K. Hill (1982) One Hundred Years of Data on Populations of Public Residential Facilities for Mentally Retarded People. American Journal of Mental Deficiency. Vol. 87, No. 1, 1-8. Pp. 1-8.

Mahler, Joan E. (1982) Alaska Division of Public Assistance Estimates of Personal Care Attendant Costs as Used in the Medicaid Home and Community Services Waiver. Juneau, Alaska. January.

Maniilaq Association (1982) Maniilaq Association 1982 Annual Report. Kotzebue, Alaska.

McDowell, Clay and Theda Mason Smith (1983) Information on Access Alaska's FY 1983 budget. Telephone conversations with Laurie Goggin, Governor's Council for the Handicapped and Gifted. Fairbanks, Alaska. July.

Morgan, Michael C. (1983) Correspondence with Laurie Goggin of the Governor's Council for the Handicapped and Gifted concerning characteristic of Vocational Rehabilitation clients, cases closed during FY 82. Juneau, Alaska. April 20.

Municipality of Anchorage (1982) Anchorage Health Systems Plan 1982-84. Anchorage, Alaska.

North Pacific Rim Health Department (1979) Ggwangkumtenck Sungcarluta. Anchorage, Alaska.

North Slope Borough (1982a) Barrow population derived from established relationships between residential electric utility connections and dwelling units, using methodology accepted by the State Demographer. Unpublished paper. Barrow, Alaska. July.

North Slope Borough (1982b) Point Lay population enumerated in January/February as part of a State-supervised North Slope Borough special census. Barrow, Alaska.

North Slope Borough (1982c) Population for villages excluding Barrow and Point Lay, census conducted by village coordinators in accordance with guidelines laid down by the State Demographer. Barrow, Alaska. July.

North Slope Borough Health and Social Services Agency (1979) Tribal Specific Health Plan, North Slope Borough. R.A. Hodge and Associates. Spokane, Washington.

North Slope Borough Health and Social Services Agency (1982) Paglan. Barrow, Alaska.

Northern Alaska Health Resources Association (1982) Health Resource Development Plan for Northern Alaska. Fairbanks, Alaska. April.

Northern Alaska Health Resources Association (1983) Respite Care Needs Assessment. Fairbanks, Alaska. January.

O'Brien, John (1982) and Connie Lyle. Focus Document for a SEARCH Conference, 1982.

Older Alaskans Commission (1983) Phone interview between Laurie Goggin and Lawry Robertson. Fairbanks, Alaska. January.

Public Health Service, U.S. DHEW, Policy Notice 78-06, 1978.

Residential Employment Alternatives in the Community for the Handicapped (1982) REACH, Inc. Program Narrative and FY 1983 Budget Proposal. Submitted to the Alaska Division of Mental Health and Developmental Disabilities. Juneau, Alaska. April.

St. Jude Center, Inc. (1982) Respite Program Proposal, 1982-1983. Submitted to the Alaska Division of Mental Health and Developmental Disabilities. Juneau, Alaska. July.

Schorenberger, R.C. (1982) Public Residential Services, 1981: Status and Trends. Mental Retardation. Vol. 20, No. 5. Pp. 210-215.

Schmidt, Rita (1983) Phone conversation re the Anchorage Community Health Services FY 1983 Budget with Laurie Goggin of the Governor's Council for the Handicapped and Gifted. Fairbanks, Alaska. July 13.

Senate Advisory Council (n.d.) Day Care in Alaska: A Status Report. Prepared by Frank W. Seuffert. Juneau, Alaska.

Sitka Parent Association for Citizens with Special Needs (1982) Sitka-PACS Respite Care Program Proposal for FY 1983. Submitted to the Alaska Division of Mental Health and Developmental Disabilities. Sitka, Alaska. July.

South Central Health Planning and Development (1982) Health Systems Plan 1982-1986. Anchorage, Alaska.

South Central Health Planning and Development (1983) Alaskan Medivacs: Descriptive Study, Identification of Problems, and Possible Solutions. Anchorage, Alaska. May.

Southeast Alaska Health Systems Agency (1982) 1982 Revised Health Systems Plan of the Southeast Alaska Health Systems Agency. Ketchikan, Alaska. February.

Southeast Alaska Health Systems Agency (1983) 1983 Mental Health Plan for Southeast Alaska. Ketchikan, Alaska.

Spence, Davis (1983) Alaska Division of Public Health, Section of Family Health, FY 83 Budget (Actual or Realized Funds) Unpublished table. Juneau, Alaska. May 25.

Tanana Chiefs Conference (1983) 1983 Overall Economic Development Plan, Attachment 1. Fairbanks, Alaska.

Tanana Chiefs Health Authority (1979) Tanana Chiefs Conference, Inc., Regional Health Systems Plan, Subregional Health Resources. Fairbanks, Alaska.

The Urban Institute (1975) Report of the Comprehensive Service Needs Study. Department of Health, Education, and Welfare. Office of Human Development, Rehabilitation Services Administration. Washington, D.C. June.

U.S. Department of Commerce, Bureau of the Census (1982) 1980 Census of Population, General Population Characteristics, Part 3 Alaska. PC 80-1-B3, Alaska. Washington, D.C. August.

U.S. Department of the Interior, Bureau of Indian Affairs (1983) Anchorage Office - Data Search. Anchorage, Alaska. May.

U.S. Department of the Interior, Bureau of Indian Affairs (1983) Anchorage Office. Data Run. Anchorage, Alaska. June.

Wolfensberger (1972) The Principle of Normalization in Human Services, National Institute of Mental Retardation, 1982, p. 29.

Yukon Kuskokwim Health Corporation (1979) Tribal Specific Health Plan, Yukon-Kuskokwim Delta. Don Bantz and Associates. Anchorage, Alaska.